### Counseling Pregnant Women and New Mothers about HIV

Counseling Practices at Siriraj and Rajavithi Hospitals and Queen Sirikit National Institute for Child Health Bangkok, 1999

# Compiled by The Bangkok Collaborative Perinatal HIV Transmission Study Group December 1999

Additional copies available (English or Thai) from:

The HIV/AIDS Collaboration
DMS6 Building, Ministry of Public Health
Tivanon Road, Nonthaburi 11000 THAILAND
Phone: (66-2) 580-5951; E-mail: rxs5@cdc.gov

# Counseling Pregnant Women and New Mothers about HIV Counseling Practices at Siriraj and Rajavithi Hospitals and Queen Sirikit National Institute for Child Health, Bangkok, 1999

### Compiled by:

The Bangkok Collaborative Perinatal HIV Transmission Study Group (see Appendix 5)

### Contributing Institutes:

Faculty of Medicine Siriraj Hospital, Mahidol University (SRR)

Ministry of Public Health of Thailand (MOPH)

Rajavithi Hospital, MOPH

Queen Sirikit National Institute of Child Health (QSNICH), MOPH

The HIV/AIDS Collaboration (HAC)

The US Centers for Disease Control and Prevention (CDC)

#### **Contributors:**

Saithip Bhengsri, BSN (HAC)

Pattarawan Chaiyakul, RN (SRR)

Sunanta Henchaichon, BNS (HAC)

Sujira Jalanchavanapate, BSW (HAC)

Bongkoch Jetsawang, BSN (HAC)

Pornwan Kajohnsee, BNS (HAC)

Kanyarat Klumthanom, BSW (HAC)

Raweewan Krajangthong, BNS (HAC)

Pimsiri Lewsrisook, RN (QSNICH)

Kanchana Neeyapun, BNS (HAC)

Chariya Prasert, BSN, MBA (HAC)

Wipada Sanyanusin, BNS (HAC)

Sumaleelak Sorapipatana, MA (HAC)

Suratsavadee Suwanmitre, BN (HAC)

Waraporn Suwannapha, RN (HAC)

Waraporn Tripanitchakul, BNS (HAC)

Chanidapa Yuvasevee, BSW (HAC)

### Coordinators/Editors:

Anna Bennetts, MPH (HAC)

Kanyarat Klumthanom, BSW (HAC)

Thananda Naiwatanakul, MSc (HAC)

RJ Simonds, MD (HAC, CDC)

Achara Teeraratkul, MD (HAC)

### Consultants:

Professor Suporn Koetsawang, MD, Faculty of Medicine Siriraj Hospital, Mahidol University

Wanna Kongsuriyanawin, PhD, Faculty of Nursing, Mahidol University

Wilai Sereesithipithak, Department of Mental Health, MOPH

Ancharee Jariyawatanawijit, Department of Mental Health, MOPH

Nathan Shaffer, MD, CDC

### Producer:

The HIV/AIDS Collaboration, Thailand

Timothy D. Mastro, MD, DTM&H, Director

Khanchit Limpakarnjanarat, MD, MPH, Adjunct Director

### **Table of Contents**

Preface i
Commentary ii
Acknowledgments
Section 1: Introduction
Section 2: Group Pre-Test Education
Section 3: Informing of Negative Results and Providing HIV Prevention Information
Section 4: Individual Counseling while Confirming an Abnormal HIV Test
Section 5: Post-Test Counseling for HIV-Seropositive Pregnant Women
Section 6: Counseling for HIV Testing of Husbands of HIV-Seropositive Pregnant Women 15
Section 7: AZT Counseling for HIV-Seropositive Pregnant Women and New Mothers 23
Section 8: Formula Feeding Counseling for Children Born to HIV-Seropositive Mothers 29
Section 9: Nutrition Counseling for HIV-Infected Children
Section 10: Counseling for Giving the Child's HIV Test Result
Section 11: Counseling for Planning the Child's Future
Section 12: Summary
Appendix 1: Pre-test education video script (English translation)
Appendix 2: Medication leaflet for HIV-seropositive pregnant women
Appendix 3: Information about PCP prophylaxis and antiretroviral drugs for infants 48
Appendix 4: Nutrition guideline for HIV-infected children
Appendix 5: The Bangkok Collaborative Perinatal HIV Transmission Study Group 51

### **Preface**

Counseling is an important component of working with people who have HIV infection and AIDS. HIV-infected people not only suffer from their physical illness, but also from psychological distress and social stigmatization resulting from lack of knowledge, misunderstanding, and negative attitudes towards people with HIV. Counseling is one way to help HIV-infected people cope with their problems and live as normal a life as possible.

During the past 8 years, a mother-infant HIV transmission research and prevention project has been conducted in Siriraj Hospital, Rajavithi Hospital, and the Queen Sirikit National Institute for Child Health with collaboration and support from the HIV/AIDS Collaboration (a joint activity of the Ministry of Public Health of Thailand and the US Centers for Disease Control and Prevention). Through this project, many research findings have been reported which have led to interventions used in Thailand and elsewhere. As a critical part of this project, hospital counselors and the research team developed a comprehensive program of counseling for HIV-infected pregnant women and new mothers. This booklet documents the counseling practices that are in use in these hospitals.

Our experience has taught us that counseling HIV-infected pregnant women and new mothers differs in many important ways from counseling other persons, because it involves families, relationships between husbands and wives, and bonding between parents and children. As a result, our counseling program has many different specific components, as reflected in the organization of this booklet.

These counseling practices were not developed through consensus among experts in the field of counseling and do not represent formal recommendations by the contributing institutions. Rather, the practices developed out of nearly a decade of daily experience in HIV counseling by nursing, social service, and medical staff working in the antenatal clinics, female STD clinics, maternity wards, and pediatric clinics, with the assistance of research nurses and social workers supported by the HIV/AIDS Collaboration to carry out collaborative mother-infant HIV prevention research studies in these hospitals. Some of the procedures adopted in these large urban tertiary hospitals may not apply to other settings as well as they do to ours. In particular, the high volume of new antenatal patients (40-60 per day), the HIV prevalence (about 2%), the availability of research staff to perform counseling, and the availability of early diagnostic testing for children may differ from other settings in Thailand or in other countries. Nonetheless, the principles and content of our counseling, and many of our procedures could serve as a beginning for other programs to modify to fit their situation.

We hope that our experience will be an example to help others counsel pregnant women and new mothers about HIV, and to help HIV-infected women overcome this crisis in their lives so that, as much as possible, they can be mothers the same as other women.

### Commentary

I was asked to write this commentary by the perinatal HIV transmission study group which has been working in the Faculty of Medicine Siriraj Hospital, Rajavithi Hospital, and Queen Sirikit National Institute for Child Health since 1992.

This important booklet is a collection of experience from counseling many pregnant women, husbands, relatives, and other involved persons. It describes essential details for learning and can be used as a guide for counseling about HIV and pregnancy, especially in relation to several key problems with which counselors often are uncomfortable.

One such problem is that of helping women to disclose HIV-positive test results to their husbands. This is important because not disclosing results can have important consequences. For example, without disclosing, it is sometimes hard for a woman to find a strong reason to ask her husband to be tested for HIV, leaving his HIV status unknown. She also may find it hard to ask her husband to use condoms. She may not know how to discuss important decisions about the pregnancy with her husband. Moreover, non-disclosure can lead to important negative psychological and emotional effects, such as worry, anxiety, distress, and feeling trapped.

One important problem which the writers address is that of HIV-infected women who have uninfected husbands (i.e., discordant couples). The way to counsel these women is described in this booklet. I would like to take this opportunity to suggest that couple pre-test counseling and couple HIV testing may be a useful alternative to help deal with these problems. Many husbands accompany their pregnant wives for the early ANC visit. Instead of just having them wait outside the room, we should invite them to participate in the pre-test counseling activities. In order to encourage husbands to learn and be aware of the problem of HIV in pregnancy, risky behavior and routes of HIV transmission should be emphasized with them. Men should have a chance to get HIV testing. When recognizing the importance of HIV testing, most couples usually agree to have couple testing and couple post-test counseling and agree to learn each other's HIV result. Couple counseling and testing also reduces the counseling workload and, in my experience, can help the uninfected husband better accept the wife's HIV positive result.

Another important by-product from this strategy will be identifying HIV-infected men whose wives are HIV seronegative. If we test only women, we miss the opportunity to protect uninfected women from infection. In addition we miss the opportunity to prevent some cases of mother-to-child HIV transmission by not retesting seronegative women who may have been recently infected and in the window period at the first test. Overall, I believe that providing couple pre-test counseling and testing as a standard ANC service would be a very worthwhile strategy.

Future planning for the child, including identifying a person to look after the child when HIV-infected parents are no longer able to do so, is another important topic described in this booklet. To be most useful, this topic should be discussed as early as the time of making a decision on continuing the pregnancy. If considered at this early stage, and if a woman can know what support she might have from potential future child care providers (e.g., grandparents or close relatives), she can make a better decision about her pregnancy. In my experience, many pregnant women who had not been counseled on this issue later found that they could not identify a future

child care provider. This caused much anxiety and stress for these women. Some women blamed the counselors or nurses who they thought persuaded them to continue their pregnancy only for the purpose of research.

I would like to mention an interesting case related to adoption of a child born to a HIV-infected mother that was encountered several years ago by the team who prepared this booklet during their counseling activities. A child was born to an HIV-infected mother who could not provide care for the child. A couple who did not have a child of their own adopted the child. They went through all the formal processes needed for adoption, but the counselor felt uncomfortable about disclosing the child's mother's HIV status to these foster parents while the child's HIV status was still not known. The counselor worried that the foster parents would be afraid of HIV and would reject the child if they learned about the child's HIV status. The counselor hoped that this child would not be HIV-infected.

As it turned out, the child was infected. The team began to worry about the possibility of HIV transmission from the child to the foster parents because the parents did not know that their child was HIV-infected and would not be aware of precautions they should take. The counselors now felt uncomfortable about disclosing the child's HIV status because they feared this couple might be angry about not being told the HIV status of the mother from the beginning, and feared the couple might abandon the child. I was consulted by phone and advised them to disclose child's HV status to the foster parents. Although I was asked by the team to talk to these foster parents and was willing to do so, I wanted the team to gain their own experience from this case. One counselor then talked to the couple and told them the whole story. Instead of feeling bad or angry, they understood and felt thankful to the counselor. The couple then went on to take good care of the child. This event increased the counseling team's faith in humanity and improved their morale.

Another issue related to humanity, moral, and economic factors is that of treatment for HIV-infected parents with antiretroviral drugs to prolong their lives and be able to provide care for their children for a longer time. This issue is seriously considered by HIV-infected women, many of whom received preventive treatment during pregnancy and then feel left out by not getting treatment after delivery for their own infections. Women are aware of antiretroviral therapy, but the problem is that the cost of long-term treatment is too high to be affordable by the government or by the women. This is still an important dilemma to be considered further.

This valuable booklet documents the long experience of counselors, most of whom received HIV/AIDS counseling training from my course. I have been providing a training course for HIV/AIDS counselors for many years with budgetary support from the Ford Foundation, European Commission, and United Nation Fund for Population Activities. I feel glad and proud of my trainees who finished this curriculum and have been able to successfully apply it to their counseling work. This booklet will provide important ideas to other readers who are doing counseling and will promote the quality of counseling in Thailand and elsewhere. Others may find that individual counseling styles and institutional practices will differ from those described in this booklet. I expect that counseling practices will continue to develop throughout Thailand.

Professor Suporn Koetsawang, MD, FRCOG Department of Obstetrics & Gynecology, Faculty of Medicine Siriraj Hospital, Mahidol University 29 November 1999

### **Acknowledgments**

We would like to thank several counseling experts who encouraged us along the way and who reviewed and commented on this document. First, we would like to express our deep gratitude to Professor Suporn Koetsawang, who was the first to teach many of us how to counsel HIV-infected people, who supported our counseling activities for many years, and who reviewed this document and wrote a commentary for it. We also thank Dr. Wanna Kongsuriyanawin of the Department of Mental Health and Psychiatric Nursing, Faculty of Nursing, Mahidol University, and Ms. Vilai Serisitthipithak and Ms. Ancharee Jariyawatanawijit of the Department of Mental Health of the Ministry of Public Health who have been very active in developing curricula for counseling training for antenatal settings in Thailand, and who reviewed this document. We would also like to thank Ms. Natapakwa Skunodom for proofreading the Thai version.

In addition, we would like to acknowledge several key persons who strongly supported mother-infant HIV counseling activities in these hospitals: Ms. Pattrawan Chaiyakul, Chief Nurse of the Female STD Unit, Siriraj Hospital and her counselor team; Ms. Jantima Kannasute, Chief Nurse of the STD Unit, Rajavithi Hospital; Ms. Boonthai In-neam, former Head Nurse of the Septic Labor Room, Rajavithi Hospital; and Ms. Pimsiri Lewsrisook, nurse and counselor in the Pediatric Infectious Diseases Clinic at Queen Sirikit National Institute for Child Health. We would also like to give special thanks to Dr. Nathan Shaffer for his strong support of HIV counseling as part of the collaborative mother-infant HIV research activities in these hospitals, and for his review of this document.

The Bangkok Collaborative Perinatal HIV Transmission Study Group December 1999

### **Section 1: Introduction**

### The role of HIV testing and counseling in mother-infant HIV prevention programs

Without intervention, about 25%-35% of children born to HIV-infected women will become infected<sup>1</sup>. In Thailand, interventions recommended to reduce this chance of infection include

### Box 1.1 Objectives of testing pregnant women for HIV

To identify HIV-infected women who may benefit from:

- informed reproductive decision-making
- preventing HIV transmission to child and partner
- improved medical and social care

To identify HIV-uninfected women who may benefit from:

knowledge about how to remain uninfected

giving zidovudine (AZT) to women during pregnancy and labor and to their newborns, and substituting infant formula feeding for breastfeeding. However, because neither intervention is appropriate for all pregnant women, HIV screening of pregnant women is necessary to target the interventions to HIV-infected women. As a result, HIV testing is central to motherinfant HIV prevention. Pregnancy is an especially important time for HIV-infected

women to know of their diagnosis so that appropriate interventions can be taken. In addition to supporting mother-infant HIV prevention programs, there are several other objectives of HIV testing of pregnant women, including allowing reproductive decision-making, preventing transmission to partners, and improved care (see Box 1.1).

The importance of counseling in promoting behavior change to prevent HIV transmission is recognized. Antenatal care (ANC) is often the only routine interaction young women have with health care systems, so ANC is an important opportunity for women to receive health promotion information, including how to prevent themselves from becoming infected with HIV. However, counseling is also critical for supporting the effectiveness of medical interventions, such as those used to prevent mother-infant HIV transmission. Counseling in this setting serves a variety of objectives (see Box 1.2). In addition to the opportunities for counseling that maternal and child health services provide, there are also many challenges to HIV counseling in this setting. In particular, pregnancy can be an especially difficult time to adjust to a diagnosis of HIV infection, because concerns about the health of the baby and the woman's future ability to care for her family may prevail. As a result, counseling during this time must deal with many difficult psychological, emotional, and social responses related to both the woman and her family. In addition, women need technical training in many new issues, such as taking medications and feeding her baby. This teaching also may be a part of counseling. It is important to provide counseling for an HIV-infected woman throughout the term of her pregnancy and beyond to assist her in making the many decisions she will be faced with on issues such as diet, finances, child

<sup>&</sup>lt;sup>1</sup> Fowler MG, Simonds RJ, Roongpisuthipong A. Update on perinatal HIV transmission. Pediatric Clinics of North America 2000;47:21-38.

care, and living arrangements. In particular, one of the most difficult times for an HIV-infected mother is likely to be when she is finding out about her child's HIV infection status.

### **Purpose of this document**

This document describes the counseling processes related to HIV testing, prevention, and care for pregnant women and new mothers at two large maternity hospitals and one large children's hospital in Bangkok, Thailand.

Rajavithi and Siriraj Hospitals and the Queen Sirikit National Institute for Child Health (formerly known as Children's Hospital) have been actively involved in research and activities related to preventing mother-infant HIV transmission for nearly a decade (see Box 1.3). In collaboration with the HIV/AIDS Collaboration (HAC), a joint activity of the Thailand Ministry of Public Health and the US Centers for Disease Control and Prevention (CDC), these hospitals have conducted a variety of research studies (See Box 1.3). The purpose of this document (printed in Thai and English), is to describe the counseling practices that have been developed at these three hospitals so that other groups in Thailand and other countries considering initiating similar mother-infant HIV prevention programs can benefit from our experience.

# HIV counseling process for pregnant women at Siriraj and Rajavithi Hospitals

To support the mother-infant HIV prevention and research activities conducted at Siriraj and Rajavithi

# Box 1.2 Objectives of counseling pregnant women about HIV

### For all pregnant women:

- inform women about HIV infection and HIV testing
- encourage HIV testing
- encourage reduction of risky behavior

### For pregnant women who test HIV-positive:

- reduce negative impact of learning of HIV diagnosis
- help obtain medical and social support
- help consider reproductive options for current and future pregnancies
- help communicate HIV result to partner, others
- offer testing to partner and support the couple during testing process
- encourage use of AZT (for herself and baby) and formula to reduce mother-infant transmission
- teach how to use AZT and formula properly
- teach how to care for child
- prepare to learn child's HIV infection status
- help plan for family's future

Hospitals and the Queen Sirikit National Institute for Child Health, it has been necessary to develop sustainable HIV counseling services by modifying and enhancing existing services in the hospital antenatal and maternity clinics and wards. The following outlines the counseling processes at these hospitals, and provides a framework for the different sections of this document.

At Siriraj and Rajavithi Hospitals, HIV counseling of pregnant women and mothers begins in the Antenatal Care (ANC) Clinic, where all pregnant women receive group pre-test education, and HIV-infected women are identified through routine HIV antibody testing. HIV-infected women are referred to the Female STD (sexually transmitted diseases) Clinic, where the counseling process continues with post-test counseling, husband counseling and testing, family planning, and counseling about preventing mother-infant HIV transmission, including AZT and infant formula use. During delivery in the Septic Labor Room, counseling is provided for taking AZT during labor. Finally, in the *Pediatric Clinic* at Siriraj Hospital and the Queen Sirikit National Institute for Child Health, counseling continues, with focus on nutrition, infant HIV diagnosis, and future planning. Figure 1 shows the different counseling modules that have been developed and indicates which section of this document contains each one.

The staffing for each of these counseling steps and the processes themselves vary between the two maternity hospitals. At both hospitals, counseling is conducted by a combination of hospital staff and HAC research staff. Approximately 10,000-12,000 women have HIV-pre-test education at each hospital each year.

# Box 1.3 About the Bangkok Collaborative Perinatal HIV Transmission Study Group

The Bangkok Collaborative Perinatal HIV
Transmission Study Group is a collaboration
among Mahidol University, Siriraj Hospital,
Rajavithi Hospital, the Queen Sirikit National
Institute of Child Health, and the HIV/AIDS
Collaboration (a joint activity of the Ministry of
Public Health of Thailand and the US Centers for
Disease Control and Prevention). This group has
been studying mother-infant HIV transmission
since 1992 using two full-time on-site research
teams, which now consist of five research nurses
and two research social workers each.

This group has contributed to several important scientific findings related to preventing motherinfant HIV transmission. The first major study (1992 to 1994) determined a reliable estimate for the rate of transmission and identified major risk factors for transmission in Thailand<sup>2</sup>. During 1996-1998 the study group conducted a phase 3 clinical trial that determined that a short course of oral AZT from 36 weeks gestation until labor and every 3 hours during labor could cut the risk of transmission in half among formula-fed infants, from 18.9% to 9.4%<sup>3</sup>. The success of this regimen led to its immediate implementation as standard practice in Siriraj and Rajavithi Hospitals in 1998, and contributed to the development of a modified short-course regimen now being implemented nationally in Thailand.

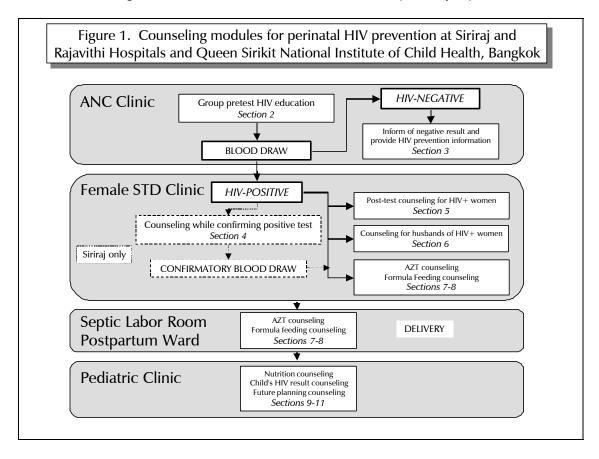
<sup>&</sup>lt;sup>2</sup> Shaffer N, Roongpisuthipong A, Siriwasin W, et al. Maternal virus load and perinatal human immunodeficiency virus type 1 subtype E transmission, Thailand. J Infect Dis 1999;179:590-9.

<sup>&</sup>lt;sup>3</sup> Shaffer N, Chuachoowong R, Mock PA, et al. Short-course zidovudine for perinatal HIV-1 transmission in Bangkok, Thailand: a randomised controlled trial. Lancet 1999;353:773-780.

With an HIV infection prevalence of about 2%, approximately 200-250 pregnant women are diagnosed with HIV infection at each hospital annually. When a woman is diagnosed as HIV-infected, her care is transferred to the Female STD clinic, including post-test counseling, husband counseling, and counseling about preventing mother-infant HIV infection. Siriraj Hospital has a team of five STD clinic nurse counselors. Rajavithi Hospital has one nurse counselor and HAC research nurses and social workers also assist in these tasks. In the Septic Labor Rooms, where HIV-infected women give birth, a labor nurse assists the woman with taking AZT during labor. The mother's post-partum counseling and care is done in the Female STD clinic. Each hospital has at least one STD nurse responsible for this counseling.

### Counseling for HIV-infected mothers at Siriraj Hospital and Queen Sirikit National Institute for Child Health

Once a baby is born to an HIV-infected mother, care of the child is transferred to the Pediatric Clinic. Children born at Rajavithi are transferred to the pediatric HIV clinic at the Queen Sirikit National Institute of Child Health; those born at Siriraj are followed up in the Siriraj pediatric HIV clinic. Counseling about the child's care is done at both hospitals by a pediatric nurse counselor.



### **Section 2: Group Pre-Test Education**

Due to the large number of pregnant women who register for care at the hospital antenatal clinics each day and the limited number of staff available, individual pre-test HIV counseling for all women

### Box 2.1 Objectives of group pre-test education

- To impart knowledge and promote understanding about HIV
- To promote acceptance of and understanding about the importance of HIV testing for pregnant women
- To reassure women that their test results will be confidential
- To inform women of the availability of measures for preventing vertical transmission: antenatal administration of AZT to mothers, formula feeding, and AZT prophylaxis for newborns

is not possible. A video was developed as a way to provide information to the large number of women in ANC requiring information before HIV testing. All women beginning ANC, which is typically in the first or second trimester of pregnancy, receive group pre-test education that includes a video and a subsequent question and answer session.

## Facilities for group pre-test education

In each maternity hospital, group education is done in a relatively quiet, enclosed room (about 3x5 meters) with adequate ventilation in the ANC clinic area. The room seats about 15 women, allowing

enough space between rows for pregnant women to walk through. A color television is installed

on a shelf high enough to be seen by all women and is connected to a video cassette tape player. A copy of the video tape "Information for women in antenatal care" is currently used (see Box 2.2, Box 2.3, Appendix 1). A trained nurse from the ANC clinic leads the group education process.

### Process of group pre-test education

First, the nurse introduces herself, orients the new ANC clients to the objectives and components of the group session, informs them that it will take 20-30 minutes, and introduces the important topics of the video. Next, the 8 minute video is shown. After the video, the nurse answers any questions the women have, reviews the key points of the video (Box 2.4),

### Box 2.2 Development of Video

The video was developed in 1992 by Dr. Suporn Koetsawang, an obstetrician at Siriraj Hospital and Mahidol University with a particular interest in HIV counseling training. The development of the video was partially funded by the Ford Foundation. The host of the video is Khun Sinjai who is a famous actress recognizable to most Thai people.

In 1998, when the two hospitals began implementing short-course AZT as standard care to prevent mother-infant transmission, new information was added to the video regarding AZT being offered to all HIV-infected pregnant women to reduce the risk of mother-to-child HIV transmission. A transcript of the video script is in Appendix 1.

# Box 2.3 Summary of key points in pre-test education

- Testing for HIV and STD is done routinely in ANC
- HIV is not confined to high-risk groups
- AIDS is caused by HIV
- HIV is invisible (i.e., you cannot tell if a person is infected, or who to be careful of as a sex partner)
- Infection of housewives by their husbands or boyfriends is common
- There are different modes of transmission (sexual, blood transfusion, mother-infant, etc.)
- The risk of mother-infant transmission in the absence of antiretrovirals is 20-40%
- Communication with husband is encouraged, especially if the wife suspects he has risky behavior
- Use of condoms is encouraged for husbands who cannot give up their risky behavior
- Being non-judgmental towards those with AIDS is important
- HIV is not spread by sharing bathroom, food, etc.
- People with HIV/AIDS are often stigmatized
- Assurance of the confidentiality of test results
- Advantages and disadvantages of taking an HIV test
- Prevention of mother-infant HIV transmission hope for new interventions
- Husband testing encouraged, especially for women who test HIV-positive
- Availability of hospital counselors
- National policy for mother-infant HIV transmission prevention-AZT during late pregnancy and newborn period, and avoiding breastfeeding

and discusses important general points about antenatal health care. Information about short-course AZT has been added to this discussion. The nurse then reviews the blood test consent form, stressing the confidentiality of test results. Individual counseling is offered afterwards to any woman who still has concerns about being tested. Women who agree to be tested are asked to sign a consent form before blood is drawn for hepatitis B, syphilis, and HIV antibody testing. Women who need more information about HIV testing are referred to the Female STD Clinic for individual pre-test counseling. After testing, women are given appointments in 1 - 2 weeks to receive results. The HIV and STD blood test screen is repeated during the 3rd trimester of pregnancy.

# Box 2.4 Key points for discussion after video

- Facts about HIV/AIDS
  - routes of transmission
  - risky behavior of self or husband
  - safer sex practices
  - non-judgmental attitudes towards HIV-infected people
- Meaning of test results
- Importance of HIV testing for pregnant women, including interventions

# **Section 3: Informing of Negative Results and Providing HIV Prevention Information**

Although most pregnant women who are tested for HIV are HIV-negative, the fact that they are engaging in unprotected sex means that they may be at risk of being exposed to HIV. Therefore, it is important that along with HIV testing, accurate and useful information be given to educate pregnant women regarding HIV prevention. However, in the setting of the busy antenatal clinics at Siriraj and Rajavithi Hospitals, it has not been practical to provide true post-test counseling for women with negative test results.

# Box 3.1 Proposed content of written materials on HIV prevention for HIV-seronegative pregnant women

- What HIV is and how it is transmitted
- What a negative HIV test means
- What behaviors increase risk for HIV infection
- How women can remain uninfected
- When to get a repeat test--in the third trimester
- Who to contact for further information

women (see Box 3.1).

Our counseling staff has been working to develop a practical way to provide HIV prevention information to pregnant women who test HIV-seronegative. As routine practice, a week after having an HIV test, a pregnant woman will come back to the hospital to receive her test result and continue antenatal care. We are developing written materials that could be given to women at this time along with informing her of her negative test results. These would include HIV prevention information targeted for pregnant

# Section 4: Individual Counseling while Confirming an Abnormal HIV Test (Siriraj Hospital only)

As discussed in Section 2, all pregnant women participate in group pre-test education to prepare them for their HIV test. After testing, women are encouraged to return to the hospital one week

# Box 4.1 Objectives of individual counseling while confirming an abnormal (positive or indeterminate) HIV test result

- To inform the woman of her abnormal test result and encourage her to have confirmatory testing and partner testing
- To assess knowledge and perception about HIV/AIDS
- To assess perception and understanding about the process of confirmatory HIV testing
- To provide knowledge and understanding about biological and psycho-social aspects of HIV/AIDS
- To prepare for post-test counseling by assessing psychological factors which are likely to impact on the ability to cope with an HIV-positive test result

later to receive their test results. Women who test HIVseropositive at Rajavithi Hospital receive post-test counseling (see Section 5). This section describes the process done at Siriraj Hospital, for women with abnormal test results (i.e., HIV-positive or indeterminate result). For these women, a confirmatory test is done before disclosing the result. At the time of the confirmatory test, the woman will be offered individual counseling, in which the counselor will determine her level of knowledge and understanding about risky behavior, assess her psychological readiness for learning her result, and obtain her written consent for confirmatory testing. If a woman

was accompanied by her husband, he will be invited to join this counseling session. In this case, couple counseling will be offered to prepare them for couple post-test counseling (see Section 6).

#### **Process**

Pregnant women with positive or indeterminate HIV test results are referred to the Female STD Unit for individual counseling for the necessary confirmatory test. Counseling is usually conducted by obstetric nurses. The duration of the session is 30-60 minutes.

### Guideline

Step 1: GREET AND MAKE RELATIONSHIP

- Greet her and make introduction.
- Begin with general or small talk to create a good relationship and help her feel comfortable with the counseling process.
- Outline what will be discussed in the counseling session and how long it will last.

Step 2: PROVIDE INFORMATION ABOUT ANC SERVICES, ESPECIALLY HIV TESTING

Review the health care service process in ANC.

- Review her understanding about blood testing and when the test results would be returned from what was told to her at the time of her first blood test.
- Ask her about whether she has had blood tests before, and if so, what kinds of tests they were and what the results were.

### Step 3: INFORM HER OF HER BLOOD TEST RESULT

- Inform her that her first blood test result was unclear and unconfirmed. Explain that because
  of this, it is hospital policy to offer her a confirmatory test. Explain that it is important to confirm
  her HIV test result to ensure proper health care management for both herself and her baby,
  particularly in case of HIV infection.
- Observe her emotional response (e.g., from facial expression and other nonverbal and verbal communication). Many women will begin to show anxiety and worry about HIV infection at this point.

### Step 4: ASSESS HER ANXIETY AND HELP TO REDUCE IT

- Assess her worry by asking her what concerns her most.
- Let her express her feelings and ventilate her worries; allow discussion to follow her concerns and provide factual explanations where possible.

# Step 5: GIVE INFORMATION ON SUBSEQUENT CARE FOR A SEROPOSITIVE WOMAN AND ENCOURAGE HER TO HAVE A CONFIRMATORY TEST

- Explain that the hospital routine practice is to do repeat blood testing for women whose ANC tests are unclear or abnormal.
- Explain that the confirmatory test is important to know for sure whether she is infected or not so that she and her baby will get the right care.
- Explain that before getting the confirmatory test, the counselor will ask her about her personal history, family, history of sexually transmitted infections, pregnancy history, and other information that may be related to the blood test results.
- Assure her of the confidentiality of blood test results and of all things that are discussed in counseling sessions, including questions she will be asked about her history and any high risk behaviors.

### Step 6: ASSESS HER HEALTH CARE BEHAVIOR DURING PREGNANCY

- Discuss her general health and pregnancy.
- Assess her ability to care for herself during pregnancy (e.g., balanced diet, sufficient rest).
- Assess her readiness to be a mother (e.g., is this a wanted or an unwanted pregnancy?).
- Assess her partner and family support.

### Step 7: ASSESS HER UNDERSTANDING ABOUT HIV/AIDS

- Review what she learned from the group pre-test education at the first ANC visit.
- Assess her knowledge and understanding about HIV/AIDS and provide additional correct and clear information, as needed.
- Explain how to interpret HIV test results (including HIV-negative, HIV-positive, window period).
- Discuss mother-infant HIV transmission rates and ways to prevent transmission, such as not breast feeding.
- Discuss using antiretroviral drugs in the last trimester, during delivery and/or for the newborn.

### Step 8: ASSESS HIV RISK BEHAVIOR OF HER AND HER PARTNER

- Ask about history of sexually transmitted diseases of both her and her partner (e.g., syphilis, herpes, gonorrhea).
- Encourage her to identify her own HIV risk behaviors (e.g., multiple partners, sex work, IDU) and those of her partner (e.g., multiple partners, bisexual, patronage of sex-workers, IDU).
- Provide information about HIV transmission risk reduction, (e.g., condom use, non-penetrative sex, abstinence) and explain the importance of HIV prevention given her unclear test result.
   Develop a plan for HIV prevention together.

### Step 9: ASSESS HER EXPECTATION OF HIV TEST RESULT AND POTENTIAL PROBLEMS

- Assess her expectation of her HIV test result.
- Discuss advantages and disadvantages of knowing one's HIV status.
- Discuss potential problems associated with being HIV-positive (e.g., stigma, loss of friends and family support, health problems etc.).
- Discuss who (e.g., partner, family) she might tell about her HIV test if it is positive.
- Explore decision-making about continuing pregnancy, future planning (i.e., ability to care for her child and ability to deal with the possibility that her child is infected).
- On the basis of her past experience, assess her potential to deal with critical situations. If there is evidence of negative coping strategies (e.g., suicidal thinking, self harm, drug or alcohol abuse) explore with her more healthy ways to deal with stress.

### Step 10: ASSESS WILLINGNESS TO HAVE THE CONFIRMATORY TEST

• Ask her opinion about and willingness to take a confirmatory blood test.

### Step 11: DISCUSS PARTNER HIV TESTING (IF PARTNER HAS NOT JOINED SESSION)

- Discuss the importance of partner HIV testing.
- If partner is not present, explore her opinion about her partner being tested for HIV and her ability and readiness to bring him to the hospital for an HIV blood test, and if desired, make appointment for partner to come to get HIV counseling and testing.
- If partner is present and willing to be tested, offer testing and follow procedures for husband counseling in Section 6.

# Step 12: SUMMARIZE ISSUES DISCUSSED; MAKE APPOINTMENT FOR POST-TEST COUNSELING

- Review all issues discussed.
- Encourage her to return to receive her HIV test result.
- Make an appointment for her to return to receive her confirmed HIV test result next week.

# **Section 5: Post-Test Counseling for HIV-Seropositive Pregnant Women**

Receiving an HIV-positive test result is likely to greatly disrupt a woman's life. Post-test counseling for an HIV-positive pregnant woman is one of the most important parts of the counseling process for HIV-infected women. The most effective post-test counseling will be conducted by counselors who are able to present the most current information about HIV, including that which is related to medical practice, health, and sexual behavior. A counselor will be more effective with a good understanding of the client's attitudes and beliefs.

Post-test counseling is an interactive process with various interrelated parts. These parts include:

- Identifying the problems and needs of the woman.
- Determining the motivation of the woman to learn all the information she needs.
- Establishing with the woman the objectives of counseling.
- Evaluating knowledge, behavior, and/or ability to change behavior. The pregnant woman needs to be knowledgeable of problems and issues facing her own and her baby's health. Having this knowledge can promote healthy behavior and help reduce HIV transmission.

#### **Process**

Informing a woman of her HIV-positive test result is done alone unless she requests that her

# Box 5.1 Objectives of post-test counseling for HIV- seropositive pregnant women

- To convey the HIV positive test result to the pregnant woman
- To ensure her understanding of the nature of HIV infection
- To facilitate adjustment to her HIV-positive status by offering support and encouraging her to have positive feelings about the near future, and to avoid feelings of dependency, helplessness, and isolation
- To give information about preventing HIV transmission to others (baby and sexual partners), personal health care, and HIV treatment
- To discuss family planning options
- To initiate the process of antenatal antiretroviral treatment for mother-infant HIV prevention

partner or someone else join her. Confirmatory test results will usually be available 1-2 weeks after the pre-test education session (Section 2). The counseling room is private and quiet. The usual duration of a post-test counseling session is 30-45 minutes. On-going counseling during regular ANC follow-up visits are offered to the woman as soon as possible following the initial post-test counseling session.

#### Guideline

### Step 1: GREET AND MAKE RELATIONSHIP

- Welcome her. Build rapport, start to create a trusting relationship.
- Allow adequate time for post-test counseling; never rush this session.
- Ensure that the counseling atmosphere is private and quiet.
- Sit with a comfortable posture so both counselor and client feel more at ease.

### Step 2: OUTLINE ISSUES TO DISCUSS IN COUNSELING SESSION

- Explain that she will be told her HIV test result during this session.
- Inform her about how long the session will take.
- Remind her of her right to know or not to know her HIV test result.
- Assure her of confidentiality of all things discussed during counseling.

### Step 3: REVIEW KNOWLEDGE AND UNDERSTANDING

- Review her knowledge and understanding of:
  - the voluntary and routine nature of HIV testing for pregnant women.
  - facts about HIV given during pre-test counseling (e.g., modes of transmission, difference between HIV and AIDS).
  - mother-infant HIV transmission, including risk factors and the use of antiretroviral treatment and formula feeding to prevent mother-to-child HIV transmission.
  - how to interpret an HIV test result.

### Step 4: PREPARE HER TO RECEIVE TEST RESULT

- Assess her expectation of her test result.
- Assess the impact HIV is likely to have on her by asking her to imagine the way having HIV
  would effect her life. Prompt her, if necessary, to imagine the possible relationship, family, and
  community implications of having HIV.
- Assess her readiness to know her HIV-positive test result by asking her directly and making an
  intuitive judgement about her readiness based upon her emotional state and the things she
  has been saying.

Before going to the next step, she should be well prepared, or she will not absorb information well. It will not be useful to continue until her anxieties have been dealt with using supportive counseling.

### Step 5: EXPLAIN TEST RESULT; OBSERVE VERBAL AND NON-VERBAL EMOTIONAL RESPONSE

- Inform her of her HIV-positive test result in a direct, neutral, supportive tone.
- Wait for her response before proceeding.
- Listen to what she says and how she says it, noticing her tone of voice, choice of words, facial expressions, and gestures.

# Step 6: EXPLORE AND HELP HER TO IDENTIFY HER MAJOR CONCERNS

- Help her consider some common concerns:
  - fear and anxiety about transmitting HIV to her infant.
  - · her own health.
  - disclosure of her HIV status to her husband. (See Section 6.)
  - family disruption (e.g., stigmatization, emotional response).

# Step 7: HELP SOLVE PROBLEMS AND MAKE DECISIONS

- Raise important issues for discussion:
  - probabilities of mother-infant transmission (antenatal, intrapartum, and postpartum).
  - prevention of mother-infant transmission by taking antiretroviral drugs.
  - decision-making regarding continuation or termination of pregnancy considering various factors influencing this decision, including the potential availability of future child caretakers and the possibility that the child might be infected (see Box 5.2).
  - provide factual information regarding pregnancy termination according to the hospital policy and procedures.
  - her notification of her partner of the test result and partner involvement in decision-making.
  - disclosure of HIV status to others; possibility of social discrimination;

# Box 5.2 Factors affecting pregnancy decisions

Possible factors promoting decision to terminate pregnancy:

- Unplanned/unwanted pregnancy
- Already having one or more children
- Poor socio-economic status, uncertain support for future childcare
- Family/ personal problems
- Fear of having an infected child
- Pregnancy in early gestation
- Symptomatic/advanced HIV disease

Possible factors promoting decision to continue pregnancy:

- Desire for child (young, primigravid)
- Good socio-economic status
- Family willingness to take care of child
- Acceptance of chance of infected child
- Pregnancy in late gestation
- Religious/ cultural beliefs
- Asymptomatic HIV disease

### possibility of social discrimination; the need for support from spouse, family, and others.

#### Step 8: PROVIDE INFORMATION AND HEALTH EDUCATION

- Provide information on the following according to hospital procedures and services available:
  - health care which may reduce or delay symptoms of HIV infection.
  - medical services for HIV-infected pregnant women and their children at the hospital.
  - family planning and birth control (tubal ligation or implantable contraceptives are offered to all women).
  - information about how to avoid high risk activities, including safe and unsafe sex.
  - antiretroviral therapy to prevent mother-infant HIV transmission.

### Step 9: ENCOURAGE HER TO ASK QUESTIONS AND EXPRESS CONCERNS

### Step 10: CONCLUDE

- Summarize or help her to summarize important points from the post-test counseling session and make necessary decisions.
- Make appointment for next ongoing counseling session (If needed).

Most women need one or more counseling sessions beyond the initial post-test counseling session to make a decision about pregnancy continuation or termination, and to accept the

Post-test counseling of HIV-seropositive pregnant women is often a very stressful session for counselors and this is considered when assigning cases. For one counselor to conduct many post-test counseling sessions in one day is not optimum.

consequences of that decision.
After post-test counseling, ongoing counseling is very important, as this assists HIV-positive women to cope with their HIV infection. In each session, one or more important issues might be discussed.

### Section 6: Counseling for HIV Testing of Husbands of HIV-Seropositive Pregnant Women

Husband counseling is done individually or as a couple, depending on the husband's test result and the preference of the couple. When a husband is HIV-positive and his wife is also

# Box 6.1 Objectives of pre-test counseling for HIV testing for husbands of HIV-infected women

- To prepare the husband to learn his HIV status
- To prepare him to face the implications of knowing his HIV status
- To impart knowledge and understanding about sexually transmitted diseases, HIV infection, and AIDS
- To provide information on the meaning of an HIV test result: negative, positive results, and the window period
- To help him assess and recognize his own risk behavior
- To encourage him to see the benefits of and feel positive about being tested for HIV

HIV-positive, consent from a couple for couple counseling is sought. In practice, couple or family counseling is often used because couples can help to solve their problems together. The situation is usually more complicated when the couple has discordant HIV test results (i.e., woman is HIV-infected. husband is HIV-uninfected). Approximately one fourth of HIV-infected women in these hospitals have HIVseronegative husbands.4 When the husband is HIV-seronegative, individual counseling is usually the first step, followed by further individual or couple counseling. Figure 2 outlines the different counseling scenarios for

husbands which may arise, and the sub-sections of Section 6 corresponding with each scenario.

### 6.1 Pre-test counseling for husbands of HIV-infected women

### **Process**

As part of the post-test counseling of HIV-seropositive women (Rajavithi) or during individual counseling while confirming a positive test (Siriraj), the woman's desires and plans for disclosure to her husband are discussed and she is encouraged to bring him to the hospital for HIV testing. When the husband comes in, pre-test counseling is given. This counseling can be done with or without his wife, according to their wishes.

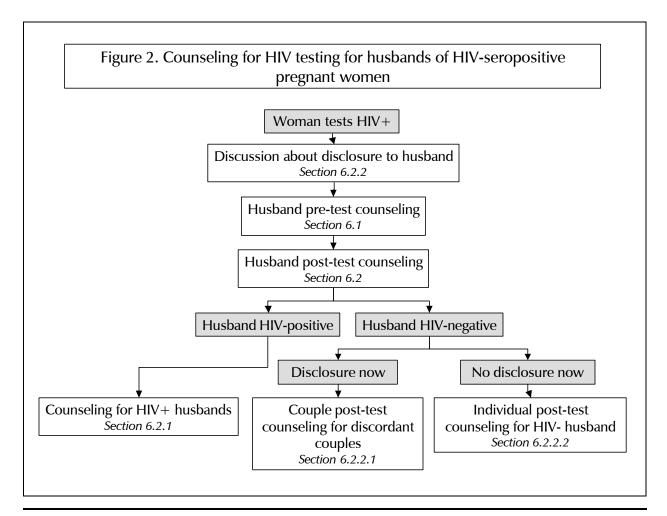
<sup>&</sup>lt;sup>4</sup> Siriwasin W, Shaffer N, Roongpisuthipong A, et al. HIV prevalence, risk factors and partner serodiscordance among pregnant women, Bangkok, Thailand. JAMA 1998;280:49-54.

Bear in mind that a woman may bring her husband to the hospital for HIV testing without telling him the reason. Do not make any assumptions about what the woman has discussed with her husband. If a man fears getting tested for HIV and he did not know beforehand that he would be asked to be tested, he may become defensive, creating a tense counseling atmosphere, and a situation where the husband will think of the counselor as his opponent. Such situations represent formidable barriers to the counseling process.

### Guideline

Step 1: GREET AND MAKE RELATIONSHIP

- Small talk; create relaxed and friendly atmosphere.
- Introduction to session.



## Step 2: ASSESS HIS EXPECTATION ABOUT COMING TO THE HOSPITAL; OUTLINE ISSUES TO BE DISCUSSED

- Assess his level of knowledge regarding the reason for his visit to the hospital. Use open questioning such as the following:
  - --Why did you come to the hospital today?
- Listen attentively to his answer. Possible answers may include:
  - --My wife wanted me to get my blood tested.
  - -- My wife asked me to accompany her.
  - --My wife said that the doctor wanted to see me but I don't know why.
- Depending on the husband's answer, use further open questions to gain more information regarding his perception of the reason for his visit to the hospital, such as:

**Husband--**My wife wanted me to get my blood tested. **Counselor--**What kind of blood test?

- If he still does not realize that he has been asked to come to the hospital to be tested for HIV, use background information from ANC pre-test counseling to introduce the issue of HIV-testing, such as:
  - --Do you know what kind of tests the hospital recommends for pregnant women?
- If a man does not have such knowledge, give him the information, such as:
  - --Here we have routine testing for syphilis, hepatitis B and HIV infection.
- Explain that his wife has a problem with her blood test, but right now we are not sure what the problem is, and her test is being repeated to find out. Ask what he thinks about that.
- Outline issues to be discussed and how long it will take.

### Step 3: ASSESS AND EVALUATE HIS UNDERSTANDING OF STD AND HIV

### Step 4: HELP HIM ASSESS HIS HIV/STD RISK BEHAVIOR

- Ask about any previous testing for STD and HIV.
- Ask about his risk behavior.
- Assess whether you think his behavior is high or low risk.
- If he has high risk behavior, offer him HIV testing.
- If he has low risk behavior, assess his expectation about his wife's HIV test result, such as:
  - --What do you think your wife's HIV test result would be?
- Attention is given to his expectation about his wife's test result, as this expectation can be revisited during post-test counseling.
- It is most likely that a husband with low risk behavior will not expect his wife to have a positive HIV test result. If that is the case, encourage him to consider alternatives, such as:
  - --What if it was not as you think?

### Step 5: ASSESS HIS WILLINGNESS TO HAVE AN HIV TEST

- Explain reasons for blood testing of husbands (i.e., HIV, syphilis, hepatitis B):
  - husband's and wife's blood tests can be different (i.e., one negative, one positive)
  - learning one's infection status can be of benefit:
    - -- if not infected, can take steps to prevent infection, especially important for couples where one is infected and the other is not
    - -- if infected, medical and other help to treat infection is possible (e.g., syphilis treatment)
  - even if both husband and wife are infected, further exposure to virus can be prevented
- Ask him if he feels he should get his blood tested as well.
- Use a client-centered approach. Do not say that you recommend him to be tested.
- Ask for consent for blood testing and assess his willingness to have an HIV test.
- If he agrees to be tested, assess his expectation about his own HIV test result.
- Assess his willingness to share test results with his wife and to have couple counseling.
- If he refuses to be tested, explore his reasons for not wanting to be tested. Try to alleviate any fears or concerns about testing he may have.
- Allow him time to decide whether or not he would like to be tested.
- If he refuses testing, be aware of any verbal or non-verbal signs of dissatisfaction with the counselor which could result in cutting off of the counseling relationship.
- Be aware of your own body language and maintain a non-judgmental attitude. Use a tone of neutrality in conversation to encourage him to be more open.

### Step 6: CONCLUDE

- Answer any questions and conclude the session.
- If he consents, send him to have blood drawn and make an appointment for post-test counseling. Explain how and where to get the HIV test.
- If he does not consent, provide education about safer sex practices.

### 6.2 General post-test counseling for husbands of HIV-infected women

#### **Process**

A week after having an HIV test, the husband will be scheduled to meet a counselor to talk about

# Box 6.2 Objectives of post-test counseling of husbands

- To provide accurate information about the meaning of an HIV test
- To help husbands prepare to receive test results and make plans after learning their HIV status
- To impart knowledge about health care, safer sex practices, preventing mother-infant HIV infection
- To promote understanding among couples and help prepare them to become parents

his test result. Ideally, the counselor is the same person who did pre-test counseling, but this may not be practical. If a new counselor takes the case, previous counselor notes are studied to understand issues pertinent to the man and his wife.

Post-test counseling of husbands of HIV-infected pregnant women is done individually or as a couple, depending on the preference of the couple and the HIV status of the husband. If the couple has discordant HIV status, in general

individual counseling of the wife and husband is used. However, couple counseling can be used if both agree to share test results.

# 6.2.1 Guideline for post-test counseling for HIV-seropositive husbands of HIV-seropositive women

Step 1: GREET AND MAKE RELATIONSHIP

- To reduce stress and anxiety, use questions showing concern and care:
  - --Did you have to wait very long?

# Step 2: REVIEW HIV/AIDS INFORMATION, INCLUDING HIV TESTING, DISCUSSED IN PRE-TEST COUNSELING

- Ask questions such as:
  - --What do you remember about what we discussed last time?

### Step 3: ASSESS HIS EXPECTATION OF HIS HIV TEST RESULT

- Ask him his expectation regarding his HIV test result.
- Clearly inform him of his HIV test result.
- Explain what the result means.
- Use silence after informing him of his result; observe and assess his feelings and emotions, and give supportive counseling to reduce his anxiety and stress.
- Assess his understanding of his HIV test result.
- Explain the difference between being HIV-infected without AIDS and having AIDS.
- Try to get the husband or couple to deal with the present and not focus on past issues.
   When both are infected, a common question is who got infected first? This could lead to conflict between the couple. Try to change their focus, saying for example:

   --HIV infection is a sexually transmitted disease, so couples often both get infected, but it is hard to tell who got infected first and it's not useful to focus on such things right now. What you should think about right now is how to plan what to do from now on.

### Step 4: ASSESS HIS PROBLEMS AND HELP HIM TO SOLVE THESE PROBLEMS

- Give information as needed regarding:
  - HIV-infection (disease progression, transmission, prevention of transmission).
  - health care for infected persons (self-care, food, exercise, stress release, reducing risky behavior, safe sex, birth control).
- Discuss social impact: (disclosure to relatives, family or friends, impact on career and plans for the future).

### Step 5: GIVE INFORMATION ON PREVENTING TRANSMISSION FROM MOTHER TO CHILD

- Give information on AZT, that it can prevent mother to child HIV transmission.
- Ask husband to participate in decision making regarding whether or not his wife and child should take AZT.
- Encourage the husband to help his wife adhere to the AZT drug regimen and formula feeding.

Step 6: ENCOURAGE BOTH HUSBAND AND WIFE TO MAINTAIN THEIR RELATIONSHIP AND PREPARE TO BECOME PARENTS

Step 7: GIVE INFORMATION ON REFERRALS FOR CARE; SUGGEST PLACES FOR FURTHER HEALTH CARE AND SOCIAL SERVICES.

### Step 8: CONCLUDE

- Answer any questions.
- Make appointment for follow up counseling.

### 6.2.2 Guideline for couple and husband post-test counseling for discordant couples

This counseling follows from the individual post-test counseling for HIV-positive pregnant women. From that session, the counselor knows the willingness of the woman to disclose her HIV status to her husband. From the pre-test counseling session with the husband, the counselor also knows his expectation of his wife's status.

Generally women do wish to disclose their HIV status to their partners, but the way that they wish to make this disclosure may vary, and intensive counseling may be needed. With discordant couples, there will ideally be two counseling sessions. The first is conducted individually with the woman, who will be aware of her HIV infection and may or may not be aware that her husband is not HIV-infected. In this session, the woman must decide with the counselor whether or not to inform her husband, and the best way to inform him of her HIV-positive status.

### Discussing with woman her disclosure of her HIV status to her husband

- Encourage the woman to consider the logical consequences of disclosure or non-disclosure of her HIV status to her husband. Help her to consider the good and bad consequences and allow her to make her own decision.
- In case she is unsure about whether to disclose or not to disclose, the counselor encourages her to think about the future, saying for instance:
  - --I understand that you are not ready to tell him right now, but when do you think you will tell him?
  - --If your baby is HIV-infected and gets sick in the future, will you have to tell your husband what is wrong with your baby?
  - -If your husband knows your HIV test result, would he give you any help?
  - -If your husband would like to have sex with you, what will you do?
- Let her take time to consider all the issues.
- In case she wants to disclose her HIV status to her husband, ask her whether she would
  prefer to disclose by herself or whether she would like the counselor to disclose for her in a
  joint couple counseling session.

After this discussion, various scenarios may ensue:

- 1. The woman may request that the counselor inform her husband of her HIV infection in a couple counseling session. Ideally this session will coincide with post-test counseling for the husband. A guideline for this session is in Section 6.2.2.1.
- Alternatively, the woman may decide to disclose her HIV-status to her husband herself either before or after he has had individual post-test counseling. When a woman wishes to tell her husband about her HIV infection herself, the counselor assesses her ability to communicate

with her husband and, if appropriate, guides her and lets her practice her communication skills in an individual counseling session.

3. For a woman who is reluctant to disclose to her partner, ongoing counseling is provided to help her realize the importance of disclosure as well as to identify and minimize the potential risks of disclosure. Because this issue is related to their personal and sexual relationship (i.e., safe sex), the husband may have questions about the wife's HIV status after he is informed of his negative result. Most women end up disclosing to their husbands after the counseling helps them understand the difficulties of not disclosing. However, some women still do not wish to disclose, and a guideline for post-test counseling of husbands in this case is given in Section 6.2.2.2.

## **6.2.2.1 Guideline for discordant couple counseling in a couple counseling session** Step 1: GREET AND MAKE RELATIONSHIP

Step 2: REVIEW GENERAL KNOWLEDGE ABOUT HIV INFECTION AND TESTING FROM PRE-TEST COUNSELING

Step 3: ASSESS HUSBAND'S EXPECTATION OF HIS HIV TEST RESULT

Step 4: INFORM HIM OF HIS NEGATIVE RESULT

Step 5: ASSESS HIS EXPECTATION OF HIS WIFE'S HIV TEST RESULT

Step 6: INFORM HIM OF HIS WIFE'S HIV-POSITIVE RESULT

- Use wording like:
  - --I could not tell you your wife's test result if she did not allow it, but she would like you to know because she told me that she never keeps any secrets from you.
- Be aware of the woman's feelings, give support (e.g., touch or hold her hand while talking to her husband).
- Emphasize the importance of love and care between a woman and a man.

Step 7: OBSERVE HIS RESPONSE; GIVE EMOTIONAL SUPPORT

Step 8: FOLLOW STEPS 5-8 OF GENERAL POST-TEST COUNSELING FOR HUSBANDS (SECTION 6.2.1). Counseling for discordant couples emphasizes preventive counseling, such as safer sex to prevent the husband from becoming infected.

Ongoing counseling is used to assess problems, including those of their sexual relationship, that have resulted from disclosure of her HIV status.

Counseling an HIV-infected woman who does not wish to disclose her HIV status to her partner can be uncomfortable, because counselors may feel torn between wanting to maintain the confidentiality of the HIV-infected woman, while also wanting to protect the HIV-uninfected partner from infection.

### 6.2.2.2 Guideline for husband post-test counseling when the wife does not want to disclose her HIV status

Step 1: GREET AND MAKE RELATIONSHIP

Step 2: REVIEW GENERAL KNOWLEDGE ABOUT HIV INFECTION AND HIV TESTING FROM PRE-TEST COUNSELING

# Step 3: EDUCATE HIM ABOUT THE HIV ANTIBODY WINDOW PERIOD; ASSESS HIS RISK BEHAVIOR

- Review his knowledge of the window period.
- Let him assess his risky behavior.

### Step 4: INFORM HIM OF HIS HIV-NEGATIVE TEST RESULT

- Evaluate his understanding of his test result.
- Suggest that he be retested in the next 3 months.

### Step 5: EXPLAIN MEANS OF PREVENTING HIM FROM GETTING HIV INFECTION

### Step 6: CONCLUDE

- Answer questions.
- If he asks the counselor about his wife's HIV result, the counselor will tell him that the test
  result cannot be disclosed without the permission of his wife. This is discussed with the wife
  during her counseling session before talking to the husband, so she can prepare to respond to
  his question herself.
- Make next appointment; end session.

# Section 7: AZT Counseling for HIV-Seropositive Pregnant Women and New Mothers

In Thailand, the HIV/AIDS Collaboration, Rajavithi Hospital, Children's Hospital, MOPH, Mahidol University and Siriraj Hospital collaborated to conduct a trial of short course (from 36 weeks gestation until delivery) zidovudine (AZT) in seropositive pregnant women. After the finding that short course AZT decreased the mother-infant HIV transmission rate in half in February 1998, this

### Box 7.1 Objectives of AZT counseling for HIVseropositive pregnant women and new mothers

- To inform the HIV-seropositive pregnant woman that taking AZT is an important option to decrease the chance of mother-infant HIV transmission
- To impart knowledge and understanding about the benefit of taking AZT to decrease the chance of mother-infant HIV transmission
- To assess the woman's readiness for and understanding of the drug-taking process
- To address any problems with compliance with the AZT regimen she may encounter in follow-up

"Bangkok Regimen" was implemented as standard of care (along with not breastfeeding) to be offered to all HIV-infected pregnant women at Rajavithi and Siriraj Hospitals. In 1999, the regimen was extended to include several weeks of infant AZT syrup as post-exposure prophylaxis.

Taking medication to prevent mother-infant HIV transmission requires several weeks of consistent treatment. For a drug regimen to work, a woman must both be motivated to use the medication, as well as understand why, how, and when to take it. For these reasons, medication counseling is a very important part of the counseling process for HIV-infected pregnant woman and new mothers.

#### **Process**

Every pregnant woman who comes to ANC at the hospital is given pre-test counseling, which includes limited information regarding AZT. After a woman tests HIV-positive she is given post-test counseling. At this point AZT is discussed; the amount of detail given at this time depends on how much information a woman is capable of taking in. Because many women will be stressed and preoccupied about their new HIV diagnosis, the amount of information able to be absorbed regarding AZT may be limited. However it is important that AZT be discussed at this time as it may give the recently diagnosed HIV-infected woman more hope regarding her unborn child's future. Either at this time, or at a later appointment, the counselor will talk in detail about AZT.

Broadly, AZT counseling consists of;

- Counseling before starting to take AZT. This includes, but is not confined to, post-test HIV counseling. Ideally, an in-depth counseling session regarding AZT is scheduled for 32-34 weeks gestation, a few weeks before starting AZT.
- Counseling at the start of taking AZT. This is one session at 34-36 weeks gestational age coinciding with the AZT start date.

- Counseling for follow up after starting AZT. After starting AZT, the woman will have an appointment each week to get a new supply of AZT and receive follow up counseling about taking AZT. During these appointments, left-over AZT and empty drug packets are returned for the counselor to assess drug compliance.
- Counseling for giving AZT to baby. Giving AZT to the baby is first discussed in general terms during counseling for giving the woman AZT during ANC. Specific counseling is done in the immediate postpartum period before discharge to home.

### Guideline for counseling before starting to take AZT

### Step 1: GREET AND MAKE RELATIONSHIP

- Outline the issues that need to be discussed.
- Encourage the client to relax.

### Step 2: REVIEW PRACTICAL ISSUES ASSOCIATED WITH TAKING AZT

- Remind her:
  - that she has been diagnosed as being HIV-infected.
  - what she should do if she is to be prescribed and given AZT by the doctor:
    - --return to the hospital each week to get AZT.
    - --return for delivery at the hospital.
    - --avoid breast feeding.
    - –give AZT to her baby.
  - that the above issues are important for maximizing the drug's effectiveness.

### Step 3: EXPLAIN THE EFFICACY AND POSSIBLE SIDE EFFECTS OF AZT

- Explain the following:
  - The efficacy of AZT (e.g., AZT is an antiretroviral medicine that can reduce the chance of mother-infant transmission by about half. That is, if 100 HIV-positive pregnant women do not take AZT during pregnancy, about 18 of these women will have HIV-infected babies, whereas if 100 HIV-positive pregnant women take AZT during pregnancy, only about 9 of these women will have HIV-infected babies).
  - That some women who take AZT may have minor side effects such as anemia, nausea, and malaise. Some babies may have mild anemia, but in general their blood should be back to normal after 1-2 months. The long-term effects of AZT are unknown, but there are no known problems up to 5 years of age in the longest studies available.

### Step 4: ASSESS UNDERSTANDING ABOUT TAKING AZT FOR HERSELF AND HER BABY

- Assess her understanding and expectation about taking AZT.
- Ask her to outline what advantages and disadvantages she sees with taking AZT and giving AZT to her baby.
- Assess her ability to follow the AZT regimen, by both asking her and listening to what she has said regarding taking AZT.

### Step 5: CONCLUDE

- Explain that it is up to her to make a decision regarding whether she would like to take AZT.
- Allow time for her to make a decision regarding whether or not to take AZT.
- If she agrees, make an appointment for her to start AZT at 34-36 weeks gestation.

### Guideline for counseling at the start of taking AZT

Step 1: REVISIT RELATIONSHIP AND OUTLINE ISSUES TO DISCUSS

- If it is the counselor's first session with her, greet her and make introductions. If not, a shorter greeting is sufficient. Create a relationship and encourage her to relax.
- Remind her of what was discussed in the counseling session before starting to take AZT.

### Step 2: EXPLAIN PROCEDURE FOR TAKING AZT

- Explain how to take AZT. She should take either three 100 mg tablets or one 300 milligram tablet twice a day, morning and evening, with food or antacids. Explain the importance of remembering to take AZT every morning and evening to help its efficacy.
- Explain what she is to do if she forgets to take her AZT. If she forgets, she should be told to take the dose as soon as she remembers. Give her an example:
  - --If you forget to take AZT after breakfast at 8.00 am and then remember at 3.00 p.m., you should take the dose at 3.00 p.m. and take the evening dose as usual, even if it's only a few hours later.

However, she should not take more than 2 doses at a time. For example:

- --If you forget your dose after breakfast and after dinner but you remember the next morning, you should take 2 doses and leave 1 dose to be returned at the next visit.
- Explain that she should come weekly for ANC visits. At these visits her AZT use for the week will be reviewed and she will be given new AZT for the following week. If for some reason she can't return for her appointment, she should take 1 dose in the morning and 1 dose in the evening using the extra AZT (3-4 doses) she will be given for such instances. She should then come for an ANC visit as soon as possible to get a new supply of AZT.
- Explain that if vomiting occurs within 30 minutes, she should take a new dose and then take the next dose as usual. If vomiting occurs more than 30 minutes after taking the dose, she should not repeat the dose as it would
- Explain that if she experiences any side effects after taking AZT she should come to the clinic. She should do this before making a decision to stop taking AZT.

have been mostly absorbed already.

- She should not take any other medicine without the doctor's permission, except for her prenatal vitamin tablets. If there are some other drugs she would like to take, she should discuss this with the doctor first.
- Inform her that at the onset of labor or water leakage she should take 1 dose immediately, making note of what time it is (See Box 7.2). After that, she should go to the hospital as soon as possible (within 3 hours). If she can't, she should take 1 dose every 3 hours until delivery. She can use the extra AZT she was given for this.

### Box 7.2 True and False Labor Pains

### True labor pains

- Regular painful contractions coming at least every 5-10 minutes and becoming more frequent and intense; or
- Leakage of yellow water that looks like urine with or without pain

### False labor pains

- Irregular painful contractions
- Lasts only a few seconds each time
- No water leakage

Remind her about the need to give AZT to the baby after delivery.

### Step 3: EVALUATE KNOWLEDGE AND UNDERSTANDING ABOUT AZT ADMINISTRATION

- Ask her about her knowledge and understanding of AZT administration and determine if there are any misunderstandings or need for more information.
- Give her the Medication Leaflet (see Appendix 2) and encourage her to read it and ask if there is anything she does not understand.
- Ask about her understanding of "true labor pain" and her understanding of when to start the labor doses. Correct any misunderstandings and explain about true and false labor pain as in Box 7.2.

### Step 4: START MEDICATION

- Give her the correct number of AZT tablets: enough for 1 week (14 doses) and extra medication (3-4 doses). Explain that this extra medication is for situations in which she may need more medication (e.g., after vomiting or at delivery).
- Advise her to take the first dose now (at the clinic). Observe any side effects that may occur, for example nausea or vomiting.

### Step 5: CONCLUDE

• Summarize the issues that have been discussed and encourage her to keep her appointment for the next visit.

### Guideline for counseling for follow up after starting AZT

Step 1: REVISIT RELATIONSHIP AND OUTLINE ISSUES TO DISCUSS

• If it is the first session with her, greet her and make introductions. If not, a shorter greeting is sufficient. Create a relationship and encourage her to relax.

### Step 2: DISCUSS ISSUES WHICH HAVE ARISEN AS A RESULT OF TAKING AZT

- Ask if she has experienced any side effects after taking the medicine, such as nausea, vomiting, or physical or social problems which have occurred in the past week (Box 7.3).
- Ask her:
  - -Did you miss any doses?
  - If yes, ask her the reasons. Ask her to think of ways she can avoid these problems in the future and explain again the importance of taking all the AZT doses.
- Ask if she has taken any other medication. If she has taken any other medication, the counselor records this and discusses with the doctor.
- Evaluate adherence by counting how much AZT she has left.
- Explain again what she should do when she starts true labor. Recap that she should take 1 dose immediately upon true labor pain, go immediately to the hospital, and continue to take 1 dose every 3 hours until delivery. Explain again about true labor pains (Box 7.2).
- Encourage her to continue keeping her ANC appointments.
- Advise her about how to take care of herself. For example, she should eat regularly and make sure that she is sufficiently rested and relaxed.
- Ask if she has any questions or any other problems she would like to discuss. Answer any questions she has and make sure that she can understand clearly the AZT information.

### Step 3: INTRODUCE INFANT AZT REGIMEN

### Step 4: CONCLUDE

• Summarize the issues that have been discussed and make an appointment for the next visit.

### Box 7.3 Common problems with taking AZT and possible solutions

Forgets to take medicine because she is too busy or does not have the pills with her:

-always bring the pills along, ask husband or friend to remind her to take pills

Afraid of others being suspicious of why she is taking the pills:

-suggest that woman tell others that this drug was prescribed by the doctor and is common for pregnant women (e.g., like vitamins or iron)

Afraid of adverse effects to her unborn child:

-remind her that no significant long-term effects have been seen with AZT

Has discomfort or other problems with AZT (e.g., nausea, vomiting):

-remind her that in general side effects of AZT are mild and will go away after a few days on treatment. If the symptoms persist or are severe, she should consult with the doctor

### Guideline for counseling for giving AZT to baby

Step 1: REVISIT RELATIONSHIP

### Step 2: REVIEW UNDERSTANDING OF INFANT AZT

- Review her knowledge on HIV mother to child transmission.
- Explain action of AZT for preventing HIV infection in baby, and also explain about potential adverse reactions (e.g., temporary anemia).

### Step 3: EXPLAIN INFANT AZT REGIMEN AND HOW TO GIVE IT

- Explain how to give AZT to her baby infant post-exposure prophylaxis: 2 mg/kg/dose (about 0.6 cc for most children), 4 times/day, for 4 weeks). Explain the importance of remembering to give AZT every day. Explain how to measure AZT syrup and techniques to give to baby (see Appendix 3).
- Explain what she is to do if she forgets to give the baby AZT. If she forgets, she should be told to give the dose as soon as she remembers. However, she should not give more than 2 doses at a time.
- Explain that if the baby vomits within 30 minutes of the dose, she should give a new dose and then give the next dose as usual. If the baby vomits more than 30 minutes after the dose, she should not repeat the dose.
- Explain that if the baby experiences any side effects after taking AZT she should bring the child back to the clinic. She should do this before making a decision to stop giving AZT.
- She should not give the baby any other medicine without the doctor's permission.
- Assess her understanding and acceptance of the regimen.

- Let her make a voluntary decision to give the regimen to her baby.
- Address potential problems and barriers to fully adhere to the regimen and help her solve the problems.

### Step 4: FOLLOW UP

• If there is opportunity for follow up sessions while giving baby AZT, assess adherence and any problems with giving AZT; help her solve these problems.

## Section 8: Formula Feeding Counseling for Children Born to HIV-Seropositive Mothers

For most children, breast-feeding is advantageous and important. Breast milk contains vital nutrients for the baby. Furthermore, breast-feeding is convenient, encourages bonding between mother and baby and can help a family to save money. In Thailand, although breast-feeding is strongly recommended for most women without HIV infection, mothers with HIV infection should not breast feed because HIV can be

transmitted from mother to baby through breast-feeding and there are safe alternatives available. The MOPH supports the cost of infant formula for those who cannot afford it.

Pregnant women who have only recently been diagnosed as HIV-infected may not be ready to disclose their HIV status to their family and may therefore find it difficult to explain to their families why they are not breast-feeding. Because of this and other reasons, counseling about formula feeding is necessary. Such

Formula feeding counseling begins in the ANC period and continues until well after delivery. This counseling is most intense immediately after delivery, but continues throughout the period in which the baby comes to the clinic for regular health check-ups.

counseling can help prepare the HIV-infected mother to confront and cope with problems which may arise from formula feeding. To maximize the success of this counseling, the counselor tries to understand the individual situation of each mother, including psychological issues, financial problems, characteristics of her family, her relationship in both the family and community, and the expectations of her husband, relatives, and neighbors regarding her pregnancy and child rearing.

### **Process**

Formula feeding counseling for a pregnant HIV-infected woman begins at the start of the

# Box 8.1 Objectives of formula feeding counseling for children born to HIV-seropositive mothers

- To impart understanding of the reasons for and importance of formula feeding
- To encourage the woman to accept formula feeding
- To assess problems she may have with formula feeding
- To help her confront and find solutions to problems with formula feeding
- To impart knowledge and instructions about how to prepare formula milk

counseling process. During ANC pre-test counseling, women are taught that the risk of mother-infant HIV transmission is increased by breast-feeding. In post-test counseling women are told of the importance of avoiding breast-feeding to decrease the chance that the baby will become HIV-infected and that formula feeding is a safe alternative to breastfeeding. Counselors emphasize proper nutrition as well as formula feeding, particularly for any baby with health problems.

### Guideline

Step 1: GREET AND STRENGTHEN RELATIONSHIP

Step 2: OUTLINE THE TOPIC TO BE DISCUSSED - THE USE OF FORMULA FEEDING INSTEAD OF BREAST-FEEDING TO PREVENT MOTHER-INFANT HIV TRANSMISSION

# Step 3: ASSESS OR REVIEW THE MOTHER'S KNOWLEDGE AND UNDERSTANDING OF THE IMPORTANCE OF AND REASONS FOR USING FORMULA FEEDING

- Assess her knowledge of the risk of mother-infant HIV transmission.
- Ask her to consider the advantages and disadvantages of breast-feeding:

### Advantages

- good nutritional and immunological content
- · no need to sterilize milk
- easy and economical to prepare
- excellent mother-baby bonding

### **Disadvantages**

- inconvenient to nurse in public when outside home
- medications, drugs, and alcohol can pass to baby
- can transmit HIV
- Ask her how she thinks she should feed her baby (e.g., refrain from breastfeeding; use infant formula).
- Provide further information regarding formula feeding:
  - · infant formula should be selected appropriate for the infant's age
  - formula should be prepared correctly according to instructions (see Box 8.2)
  - formula should be the main food for the first year of life, but other foods can be introduced as the child grows.
  - if the child is allergic to cow's milk, the doctor may recommend other formula such as soybased milk.
- Assure her that infants can be successfully formula fed:
  - formula has good nutritional content and different types of formula are available for different ages of infants.
  - mother-baby bonding can be enhanced by holding the baby in the same position as if breastfeeding, and frequently cuddling, touching, and talking to the baby to express love and caring.
- Provide information regarding governmental and non-governmental services which provide formula milk powder.

### Step 4: EXPLORE ANY OBSTACLES TO FORMULA FEEDING

- Explore the following:
  - her psychological condition, her attitudes, beliefs, and prior expectations about breastfeeding (e.g., quilt she may feel about not breastfeeding).
  - potential problems envisaged with formula feeding, such as with her family, her neighborhood, or her community (e.g., involuntary disclosure of her HIV-positive status).
  - any economic problems including increased expenditure or unemployment.
  - potential problems with formula milk preparation and feeding due to lack of experience.

Step 5: PROVIDE SUPPORTIVE COUNSELING TO HELP OVERCOME OBSTACLES; ASSESS HER ABILITY AND MOTIVATION TO FORMULA FEED

Step 6: ASSESS ABILITY AND KNOWLEDGE ABOUT HOW TO PREPARE FORMULA MILK

- Provide advice about home hygiene and sanitation (e.g., kitchen and pantry area).
- Assess whether she has access to a source of clean water to prepare formula milk.
- Assess her ability to prepare, care for, and clean the bottles, nipples, and other utensils.
- Assess her ability to prepare formula and her knowledge of formula feeding techniques.

Step 7: CONCLUDE THE COUNSELING SESSION AND GIVE HER A CHANCE TO ASK QUESTIONS; GIVE HER THE LEAFLET "INSTRUCTIONS ON HOW TO PREPARE FORMULA MILK AND UTENSILS" (BOX 8.2)

Step 8: MONITOR AND EVALUATE THE EFFECTS OF FORMULA FEEDING ON THE FAMILY WHEN THE MOTHER BRINGS HER BABY TO THE CLINIC

### Box 8.2 Instructions on how to prepare formula milk and utensils

- 1. Thoroughly wash the feeding bottle, nipple, cap and any other utensils with clean water, and clean the bottle and nipple with liquid detergent.
- 2. Boil all utensils for 10-20 minutes.
- 3. Store utensils in clean and top-covered containers.
- 4. Wash your hands before using utensils. Avoid directly touching utensils, especially bottle nipples, as germs can be spread from your hands while preparing milk.
- Mix powdered milk with boiled water and lukewarm water in a clean bottle. The mixing must be performed strictly in line with the proportion indicated on the label. Shake well before feeding.

### Note:

- Boil water used for formula for at least 10 minutes. Pour some boiled water into a sterile container with a cover on top. Leave it to cool down. It will be used together with boiled water when preparing milk, and will be fed to the baby after milk feeding.
- It is possible to prepare formula milk in many bottles at the same time. But milk must be kept in the refrigerator and consumed within 24 hours. Discard the milk remaining after 24 hours. Each bottle of milk taken from the refrigerator should be warmed before feeding by putting it briefly in hot water.
- Milk that is too diluted or too concentrated may have inadequate nutritional value for baby and may be hazardous to the baby's health.
- Cover the powder can lid firmly each time after use. Keep it in a dry and cool place. The powdered milk should be finished within 1 month after the can is first opened.
- While feeding, occasionally put the baby face down across the shoulder to burp. Lay the baby on the right side, to prevent the baby from vomiting.
- Feed some cool, boiled water to baby after feeding formula to clean the baby's mouth.

## Section 9: Nutrition Counseling for HIV-Infected Children

The growth and development of a baby normally depends on his/her physical and mental care. Mothers or other care-takers must have knowledge and understanding of nutrition for babies and must be able to prepare food which is appropriate for their baby's changing age. This will maximize the chance that a baby will grow up with good health. Good nutrition as well as correct immunizations will reduce the chance that a baby gets sick. Furthermore, food is important for the mental development of a baby. As stated earlier, in Thailand health care providers suggest that HIV-infected mothers should replace breast feeding with formula feeding. Otherwise, the nutritional advice for mothers of HIV-infected and uninfected babies born to HIV-infected mothers

# Box 9.1 Objectives of nutrition counseling for HIV-infected children

- To provide mothers with knowledge, understanding, and practical advice about nutrition for HIV-infected babies who start to fall sick
- To explore any problems associated with or obstacles to preparing food for the ill baby at home, and to help provide solutions to these problems
- To encourage and support the mother or care-taker in feeding the child
- To assess family support and the mother or care-taker's ability to take care of the baby's nutrition at home

is the same as that which would be given to any other baby. Each baby should get supplements appropriate for his/her age. A general nutritional guideline for all babies, based on different ages can be found in Appendix 4.

HIV-infected babies who begin to fall sick from infections may become delayed in growth and development. Early HIV-related symptoms in infants often are loss of appetite, oral problems, nausea, vomiting, or chronic diarrhea. Appropriate calories, proteins, vitamins and minerals will help build the body's immune system as well as protect the baby from opportunistic infections. Furthermore, a nutritious diet can help prevent malnutrition and support appropriate energy conservation.

While preparing food, cleanliness, safety, and hygiene should be major concerns from the provision of raw materials to the feeding procedure itself. Mothers are told to always wash their hands before preparing food, to keep all food utensils clean, to cook raw meat until it is well-done, to wash vegetables and fruits, and to keep food in an appropriate and hygienic place.

### **Process**

When an HIV-infected mother brings her baby to the clinic for regular check-ups and immunizations, she will get ongoing counseling on health care, formula feeding, and diet. An HIV-infected baby beginning to have symptoms, such as chronic diarrhea, oral thrush, anorexia or weight loss, may get treatment from the doctor. The counselor must follow the baby's health status, treatment, and results of the treatment, and provide nutrition counseling for the mother of the ill baby. By doing so, illnesses caused by any intervening diseases can be addressed more broadly than by medical treatment alone. However, as it takes some time for a definitive HIV

diagnosis for a child (12- 18 months), the HIV status of the ill child may not be known. The counselor is aware of this and deals with the issue of the child's HIV status sensitively.

### General nutrition counseling guideline for HIV-infected babies

Step 1: GREET AND STRENGTHEN RELATIONSHIP

• Talk about child care and family situation at home.

Step 2: INTRODUCE FOCUS OF COUNSELING SESSION - NUTRITION FOR A BABY HAVING HEALTH PROBLEMS

Step 3: ASSESS KNOWLEDGE AND UNDERSTANDING ABOUT THE IMPORTANCE OF NUTRITION TO THE BABY'S HEALTH

### Step 4: ASSESS BABY'S HEALTH

- Assess body height and weight.
- Assess development.
- Ask mother if there are any abnormal signs, such as abnormal eating behavior or chronic diarrhea.
- If the baby has been medically treated, ask the mother if there have been any changes in the baby's health since starting treatment.

### Nutrition counseling guideline for ill HIV-infected babies

Step 1: ASSESS CONCERNS OF THE MOTHER / CARETAKER ABOUT CHILD'S ILLNESS

- Ask mother or caretaker about concerns regarding the baby's sickness.
- Assess coping mechanisms, including family support.

Step 2: HELP LESSEN WORRY AND OFFER ENCOURAGEMENT ABOUT CARING FOR THE ILL BABY

Step 3: GIVE NUTRITIONAL ADVICE IN LINE WITH THE BABY'S ILLNESS (See Appendix 4)

- Look into any problems and difficulties she is experiencing associated with food preparation at home and help to solve problems.
- Give pamphlets or other written information as appropriate to her education level to help her gain more understanding of how to look after the baby.

### Step 4: CONCLUDE

- Answer any questions she has.
- Emphasize the importance of bringing the baby for medical check-ups according to the schedule set by the doctor.

## Section 10: Counseling for Giving the Child's HIV Test Result

Counseling for informing a mother of her child's HIV test result is part of the counseling process which begins in ANC with the HIV-infected pregnant woman (and partner when possible), and continues through the postpartum period. This counseling aims to prepare the parent(s) to know about their child's HIV status and may include follow-up counseling after the child's diagnosis is known. Because much hope and expectation is focused on the child's HIV status, counseling regarding the baby's HIV test result needs to be conducted sensitively by a counselor who has a good understanding of the client's needs and difficulties. Learning a child's HIV status can have profound effects on the mother's emotional state due to the strong bond between mother and child and the importance of the child to the family. Difficulties which are likely to further impact on a parent's emotional state at this time include problems related to HIV illness (e.g., the death or illness of the mother or partner), other psycho-social problems (e.g., family disclosure, stigma) and other non-HIV related issues.

# Box 10.1 Objectives of counseling for giving the child's HIV test result

- To prepare the client (e.g., mother) before informing her of her child's HIV test result
- To assess her mental and emotional status before informing her of the child's HIV test result
- To assess problems before and after informing her of her child's HIV test result
- To offer psycho-social support and minimize adverse mental and emotional reactions, particularly if the child is HIV-infected
- To provide essential and accurate information regarding future care of the child

### **Process**

### 1. Clients

Counseling about the child's result is different from other counseling about HIV testing because the counseling is not directed to the person tested, but to his/her parents and possibly even others who provide child care and guardianship. The "client" therefore could be:

- Mother
- Mother and father
- Other child caretaker who could be the child's relatives

In this guideline we assume the client to be the mother of the child, as this is the most common scenario. Where the caretaker is not the mother, disclosing the child's

HIV status may inevitably also involve disclosing the parents' HIV status. This is done in consultation with the parents where possible. The positive and negative effects of this disclosure to all parties, particularly the child, must be considered carefully before such disclosure.

### 2. Roles

Doctors, nurses, and counselors all play important roles in informing a family about a child's HIV status and helping them cope with the emotional, social, and medical consequences. Sometimes the counselor may be a nurse and play two roles.

• **The counselor** prepares the parents, assesses their readiness to know their child's HIV result, and talks with the doctor and nurse to learn about the child's planned medical care. The

counselor provides ongoing support to the parents after they learn their child's HIV status from the doctor.

- The attending doctor directly informs the parents of their child's HIV status after learning from direct discussion with the counselor or by reading the counselor's notes about the parents' readiness to hear the diagnosis.
- **The nurse** follows the child's health and development, provides advice on caring for the child, and coordinates communication between the doctor, counselor, and family.

### 3. Timing

Counseling begins in ANC and continues in the post-partum period. During the post-partum period mothers come to the hospital for postpartum and child follow-up and vaccination visits. Counseling regarding their child's HIV result starts at the beginning of the counseling process and intensifies as the time for learning the child's HIV status (see below) gets closer.

### For infected children

- For asymptomatic children: at 9 months of age (after positive result of 6 month PCR is known) or at 21 months of age (after positive result of 18 month antibody test is known).
- For symptomatic children younger than these ages: when preparing to start antiretroviral or prophylactic drugs.

### For uninfected children

 At 15 months postpartum (if antibody test result is negative at 12 months) or at 21 months of age (if result is positive at 12 months but negative at 18 months).

### Guideline

Child's result counseling consists broadly of 3 parts:

- Counseling before disclosing a child's HIV status.
- Counseling for disclosing a child's HIV status.
- Counseling after disclosing a child's HIV status.

In clinical situations where PCR testing is not available, health care providers may not know a child's HIV status definitively before 12-18 months of age. Therefore informing parents of the HIV status of all children - both infected and uninfected - may occur at a later stage.

### 10.1 Counseling before disclosing a child's HIV status

Step 1: GREET AND MAINTAIN RELATIONSHIP; CLARIFY COUNSELING GOALS (EVERY VISIT)

- Small talk.
- Assess current family background, child's health and any problems she is facing.
- Ask her to assess her child's health, growth and development after birth.
- Clarify issues to be discussed in this session, including schedule for child health check up and blood tests for child's HIV status.

### Step 2: ASSESS KNOWLEDGE OF HIV TRANSMISSION FROM MOTHER TO CHILD

- Review schedule of child follow up for physical examination and blood testing.
- Review her knowledge of probability of mother-infant HIV transmission and progression of HIV disease for an infected child.
- Review her comprehension of the effect of AZT to reduce, but not eliminate, the probability of mother-infant HIV transmission.
- Discuss HIV transmission via breast milk, also any problems she is having with formula feeding.

# Step 3: ASSESS HER EXPECTATION OF THE CHILD'S HIV STATUS AND READINESS TO LEARN HER CHILD'S RESULT

- Assess any expectation she has from taking AZT.
- Assess her feeling and expectation about her child's status.
- Assess her need for support when learning her child's status.
- Assess her problems and worries.
- Allow her to consider the impact on her of learning about either a positive or negative result.
- Discuss the plan for her child both if the result is positive and if the result is negative.
- Discuss disclosing the child's HIV status to others.
- Assess her physical and mental readiness to hear the result.
- Tell her when the doctor will inform her of her child's HIV status.

Counselors are in close contact with mothers of infected or symptomatic children, and counseling follow up is attempted at every postpartum visit.

### 10.2 Counseling for disclosing a child's status

Step 4: DISCLOSE CHILD'S HIV STATUS (WITH ATTENDING DOCTOR)

- Clarify the goal of the session -- to disclose the child's HIV status.
- Review her understanding of HIV testing for children.
- Discuss her worries/concerns.
- Disclose her child's HIV status and clarify the meaning of the test result.
- Encourage her to ask guestions and ventilate her worries.
- Provide medical information on the child's health care:
  - For an uninfected child
    - -- Inform about the next follow-up appointment for the child and discharge child to the regular baby clinic.
  - For an infected child
    - -- Explain the use of antiretroviral drugs and PCP prophylaxis (Appendix 3).
    - -- Provide information about ongoing care and explain the importance of seeing a doctor regularly.

### 10.3 Counseling after disclosing child's status

Step 5: PROVIDE SUPPORTIVE & ONGOING COUNSELING

### Uninfected child

- Review her understanding and interpretation of her child's status.
- Further educate her about how to live with her uninfected child transmission issues (e.g., avoiding child contacting her blood).
- Educate her regarding her child's care (including formula feeding and nutrition).
- Educate her regarding the child follow up schedule for regular check ups.
- Discuss her plans for the future, including who she thinks may be able to provide long-term care for her child (see Section 11).
- Assess child's living and family situation, including the physical and emotional situation. If there are problems, such as financial difficulties, consider referral to an appropriate social service organization.

### Infected child

- Assess her emotional state and encourage her to express her feelings.
- Review her understanding and interpretation of her child's HIV-infected status.
- Assess any problems associated with having an infected child that she is experiencing.
- Help her predict and/or solve any problems resulting from having an HIV-infected child (e.g., need for frequent medical care).
- Help her cope with knowing her child's infected status and encourage her to plan for the future of the family.
- Assess her ability to care for her HIV-infected child (e.g., medical visits, giving medications).
- Discuss disclosure of her child's HIV status to others.
- Support and encourage her potential to cope with her HIV-infected child.
- Reinforce how to care for her infected child (including formula feeding and nutrition).
- Conclude the session and advise her to return for regular medical care (for herself and her child) and counseling.

## **Section 11: Counseling for Planning the Child's Future**

During counseling regarding planning a child's future, an HIV-infected mother will have the opportunity to talk about and plan for the future care of her child. Issues to be discussed are family-focused because the quality of the child's life depends on the quality of the family's life. Planning for the future of children with HIV-infected parents not only helps these children and their

# Box 11.1 Objectives of counseling for planning the child's future

- To identify and assess her current needs and problems and to determine what support is available to her
- To encourage a positive attitude towards living with HIV
- To initiate and assist her in the process of planning for the child's future
- To inform her about social service organizations and supportive networks available, and to coordinate any appropriate referral

families affected by HIV, but can also lessen the burden that orphans place on society. During the counseling session, counselors should be aware that HIV-infected parents are likely to have physical and emotional problems themselves, such as death or illness of a spouse, worries about the child's future. and worries about their own death. This type of counseling is very sensitive and can elicit gloomy feelings because of the implication of the eventual loss of the parents' own life and ability to care for their child or children in the future. Therefore, it behooves the counselor to give maximal supportive counseling that focuses on promoting the courage to live with HIV-infection and encouraging the mental strength to plan, manage, and prepare for future family problems. A counseling technique that is important for

this session is allowing the woman the opportunity to express and reflect on her experiences with coping with her HIV infection and her role as a mother. This can allow both the counselor and mother to appreciate the strengths she has which can be utilized to help her cope with planning for her child's future care.

### **Process**

In general, when the baby's HIV result becomes clearly defined, the mother's readiness to learn her baby's HIV status will be assessed by the counselor. She will then be notified by the doctor or counselor of her baby's HIV test result (see section 10). After this time, uninfected babies will be referred for routine hospital follow-up, and infected babies will receive ongoing care at the pediatric HIV clinic. The process of planning for the child's future begins at the time of notification of the child's HIV test result.

### Guideline

Step 1: GREET, STRENGTHEN RELATIONSHIP, ASSESS PHYSICAL AND MENTAL STATUS

Step 2: SURVEY HER PROBLEMS AND NEEDS

Assess mental state carefully.

• If her emotional state is stable, or she knows how to solve her current problems, then go to step 3. If her problems are very complicated or a solution cannot be found, refer her directly to a relevant organization.

If the woman is not ready to discuss the future because she has emotional problems (e.g., signs of depression or anxiety), try to determine the cause of the emotional problems and explore solutions before proceeding.

### Step 3: PREPARE TO DISCUSS FUTURE PLAN FOR CHILD

- Discuss the family's current status including health, income, family relationships, and care of the child.
- Encourage her to face any problems which currently affect the care of the child. Try to create a positive attitude towards living with HIV infection.
  - Assess how she has accepted her own HIV status, her adjustment to her status, and the
    consequences of knowing her HIV status by asking her about her life after her diagnosis,
    her physical and mental health, her family situation, and other related issues.
  - Determine her ability to cope with problems by asking how she has dealt with them—for example asking:
    - --How have you managed to endure the suffering you have experienced since learning of your HIV infection?

Let her talk freely about her feelings and emotions.

- Help her summarize her feelings, identify successful coping strategies she has used to cope with problems in the past, and point out other strengths in her character.
- Point out the love and other support she has received from her family and friends.
- Discuss with her that HIV infection is just one part of her life, and there are other important parts, such as having children, watching them grow up, and taking care of those who are relying on her.
- Provide some realistic hope that there could be future research findings to help people with HIV infection to live longer.
- Promote the positive aspects of motherhood, including love and bonding between mother and child.
  - Discuss the woman's experiences and feelings about having a baby, emphasizing the positive feelings, such as pride of motherhood, happiness, and her warm relationship with her baby. Let her talk freely about her feelings and emotions.
  - · Discuss her thoughts on her child's future.
  - Ask her to reflect on the care, love, and bonding she has given her child, including the efforts she has taken to prevent her baby from getting HIV infected.
  - Ask her to reflect on the situation from her child's perspective—the tenderness and love the child must feel for her, and that no one can provide the kind of love and care that she can.

### Step 4: INTRODUCE PLAN FOR CHILD'S FUTURE

- Review and check the perception and understanding of the child's HIV test result.
- Determine disclosure of woman's HIV status to her family.
  - Ask whether she has already disclosed her HIV status to her family.
  - If she has, identify who she disclosed to, and the consequences of the disclosure.
  - if she has not:
    - -- ask her why not.
    - -- ask her about problems she has with disclosure and help her to reflect on these.
    - -- help her explore her problems and ways to solve them.
    - -- help her consider the possible good and bad effects of disclosure, especially related to future care of her child.
- Discuss her future plan for taking care of the child. Ask her if there is a potential caretaker who could take over when she is not able to care for her child anymore, for example:
  - --Have you planned who the future child caretaker will be? Have you ever discussed this with your husband or relatives?

### Step 5: IDENTIFY AND DISCUSS A POTENTIAL FUTURE CHILD CARETAKER (PFCC)

- Offer examples of PFCC (e.g., grandparents, other relatives, friends).
- Assess the relationship between PFCC and the child. In case there is no current close relationship, encourage her to attempt to form one.
- Determine what PFCC's perception of, understanding about, and level of acceptance of the mother's HIV status and the child is likely to be.
- Ascertain whether the mother has or has not disclosed her HIV status to PFCC.
- If not, ask her if she has a plan to disclose her HIV status. Discuss attitudes held by PFCC.
- Explore ways to ascertain the attitudes held by PFCC.
- Suggest giving PFCC some information about HIV/AIDS in order to assess his/her attitudes.
- Explore ways to encourage PFCC to have a positive attitude towards HIV-infected people.
- If the child is infected, explain that PFCC needs to be informed of the child's HIV test result, in order to take care of the child when he/she is sick.
- Assess the caretaking potential and suitability of PFCC including such issues as his or her age, occupation, income, and child and health care experience.
- Determine other possible PFCCs, in case the first choice refuses or is not appropriate.

# Step 6: IF SHE HAS NO POTENTIAL PFCC, GIVE HER INFORMATION ABOUT SOCIAL SERVICE ORGANIZATIONS (BOTH GOVERNMENTAL AND NON-GOVERNMENTAL), AND REFER WHEN APPROPRIATE

## Step 7: SUM UP AND MAKE NEXT APPOINTMENT, IF NECESSARY

Tell her she can come back and discuss these issues further at any time.

### Step 8: FOLLOW-UP AND EVALUATE AT NEXT VISIT

- Identify and help solve problems associated with PFCC chosen, such as:
  - mother cannot disclose her HIV status to her family.
  - · the choice for PFCC refuses.
  - the choice for PFCC is unable to provide adequate child care (e.g., lacks skills, resources).

## **Section 12: Summary**

In this booklet, we described the procedures and content of counseling performed in support of mother-infant HIV prevention programs at Siriraj Hospital, Rajavithi Hospital, and Queen Sirikit National Institute of Child Health in Bangkok, Thailand as of 1999. The purpose of the booklet is to inform other health and social workers involved in mother-infant HIV prevention activities in Thailand and elsewhere of a counseling model that has evolved to work well in our settings.

Other important documents address HIV counseling for pregnant women in Thailand<sup>5</sup>. A publication of the Thai Ministry of Public Health (Department of Mental Health) is an excellent source of training materials for counselors in this setting<sup>6</sup>. Other guidance for counseling is provided by UNAIDS and other international organizations<sup>7</sup>.

Based on our experience, two points deserve attention about HIV counseling staff, whether they be dedicated counselors, or health care staff who perform counseling among other duties. First, the cumulative strains that HIV counseling places on staff may cause the staff themselves to begin to suffer from emotional and psychological distress. Staff in charge of counseling teams, and members of the teams should be aware of the difficulty that they are facing, and where possible, support each other and try to minimize stress in the workplace. Some of the counseling topics addressed in this book (e.g., post-test counseling of HIV+ women, counseling of discordant couples, counseling about future care of child) can be particularly stressful, even for experienced counselors. Peer support groups can be started within which counselors can present cases, share problems, and ask for advice from colleagues. When possible, the number of difficult cases handled by a counselor in a day should be limited. Second, counselors need to receive training and periodic re-training to assure that their knowledge and skills remain up-to-date. In busy antenatal and pediatric clinics, counselors may play a substantial role in communicating and interpreting technical information about medical conditions and treatments to patients, and their information should be accurate and current.

Improvements in counseling are needed in several areas to better serve the population of pregnant women in Bangkok, other parts of Thailand, and other countries. First, women who do not get antenatal care miss many of the benefits of HIV testing and counseling. Nonetheless, because some interventions to prevent mother-infant HIV transmission must be started soon after birth (e.g., not breastfeeding), HIV testing during labor can allow an important prevention

<sup>&</sup>lt;sup>5</sup> Koetsawang S (ed). Counseling [in Thai]. Samcharoenpanich Publishers (Bangkok), Ltd. March 1999.

<sup>&</sup>lt;sup>6</sup> Department of Mental Health, Thailand Ministry of Public Health. Manual for Counseling and Training: To reduce mother to child transmission in HIV-infected pregnant women [in Thai]. Ministry of Public Health: Bangkok, Dec 1998.

<sup>&</sup>lt;sup>7</sup> UNAIDS. Counseling and voluntary HIV testing for pregnant women in high HIV prevalence countries: elements and issues, Best Practice Collection. Geneva, UNAIDS, October 1999.

opportunity for these women. However, the best way to provide information about testing and post-test counseling to a woman in labor is not known and should be determined. Second, in Thailand, AZT treatment of HIV-exposed infants is now a standard part of the regimen to prevent mother-infant HIV transmission<sup>8</sup>, and more experience with counseling to support good adherence to this treatment is needed. Third, many young women in Thailand move frequently to take new jobs or for other reasons. For HIV-infected women, this presents challenges for the continuity of counseling and treatment needed to support their care and mother-infant HIV prevention interventions. Thus, strategies to adapt to a mobile population, such as developing effective referral networks, are needed. Fourth, more could be done to improve preventive counseling for women who test HIV-negative. Creative measures which use less staff time and resources, such as written materials, videos, group sessions, or other such measures, should be developed to allow more effective prevention counseling. Fifth, strategies to more fully engage husbands in HIV counseling related to HIV prevention and other ANC programs is needed. Finally, if possible, the extent to which counseling improves the quality and increases the acceptability and effectiveness of mother-infant HIV prevention services should be better studied.

<sup>&</sup>lt;sup>8</sup> Kanshana S, Thewanda D, Teeraratkul A, et al. Implementing short-course zidovudine to reduce mother-infant HIV transmission in a large regional pilot program in northeastern Thailand. AIDS, in press.

## **Appendix 1: Pre-test education video script (English translation)**

**Background Voice**: With best wishes for a happy family life and with concerns for every mother's well being.

**Opening Caption**: "Knowledge About HIV/AIDS for Pregnant Women Visiting an Antenatal Clinic."

**Sinjai**: Many expectant mothers will be surprised that in addition to testing for syphilis and hepatitis B virus, nowadays doctors will routinely test for HIV infection as well.

**Sinjai**: Yes, many may feel a bit annoyed and many may want to say that I couldn't care less. Even I myself used to wonder why the doctor had to test me when I went for my own prenatal visit. Was he prejudiced against me to think that I may have contracted HIV? But after discussion with the doctor, I realized that sometimes our understanding about AIDS is way off the mark.

**Sinjai**: We tend to think that AIDS is a disease confined to people such as sex workers, homosexuals, and drug addicts. But in fact anybody can contract the disease nowadays. Since the discovery of the first AIDS case in Thailand not too long ago in 1984, it has spread to members of every age group, socioeconomic class, and profession.

**Female doctor speaking to Sinjai**: As you know, AIDS is caused by a virus destroying the body's immune system. Initially, the virus does not cause any symptoms. It takes from 5 to 10 years or longer before the body is weakened to the point that it cannot fend off germs as well as non-HIV infected persons. Infected people will become sick very often with more severe symptoms and may die from them. The problem is that because it takes a long time from the point when patients first contract the virus before they become sick, they are unaware of the HIV infection...(pause to allow audience to think)

**Sinjai**: and will infect other people unknowingly.

**Doctor**: Exactly, we women can be infected by husbands or boyfriends. Today, there are already a large number of infected housewives.

Sinjai: Their husbands probably did not intentionally infect them, but because they didn't know...

**Doctor**: Yes... they didn't know. They don't even know for how long they have been infected, perhaps even before they were married.

**Doctor**: AIDS can be contracted through sexual intercourse, blood transfusion, and through sharing of needles and syringes by drug addicts. Men who sleep with prostitutes or engage in extramarital affairs may contract AIDS just like any other sexually transmitted disease. We have to be careful because AIDS may reside in the body of the very person about whom we may have the least suspicion.

**Sinjai**: For us women, I think, if we suspect or think that our husbands are still going out with other women or seeking out the service of prostitutes, then we should raise this issue for discussion to let them know that we care and are genuinely concerned about their safety. They should always use condoms for self protection if they can not give up these sexual habits.

*Sinjai*: This is important because AIDS can be transmitted from fathers to mothers and then to children in the womb. Not every child will be infected, doctors say that for every 100 HIV-infected mothers, about 20-40 newborns will be infected.

**Sinjai**: I think as of today to presume that those who have AIDS are bad persons or sexually promiscuous is probably not quite right. Nobody wants to be sick, however sometimes a certain group of people have no choice but to expose themselves to the danger of HIV infection by the very nature of their profession. Some people may blunder or err because they are drunk while having sex; if we are not careful, all of us can contract HIV too. We should be sympathetic to their plights rather than being judgmental.

**Doctor**: I say that AIDS should not be looked at with revulsion because it can not be casually contracted like a case of flu.

**Doctor**: AIDS does not spread through conversation, casual contact, sharing of personal belongings, dining at the same table, or using the same bathroom or swimming pool with HIV-infected persons. And it also does not spread through mosquito bites like many people may fear. During the asymptomatic period, people with HIV infection can function perfectly as members of society. However, there still are people who harbor deep misunderstandings about this disease, such as those who shun social contact or avoid coming close to HIV-infected persons. The hospital will therefore keep the result of the HIV blood test strictly confidential. It will disclose the test result only to the patient and the persons to whom the patient is willing to divulge the information.

**Sinjai**: Usually we don't go for an HIV blood test for no reason, but I think since the hospital offers the service, we might as well go for it. If we are tested negative, it will be very reassuring and we will be more earnest about protecting ourselves and our husbands. Now, some of you may ask what if the result is positive, wouldn't it be better if one remains oblivious to the fact instead of being devastated by the test result? I can empathize with you on this score, but I think knowing a positive test result has its advantages too. We can prepare ourselves physically and psychologically to make decisions and plans about our children, our families, and our future.

*Sinjai*: Moreover, the doctor has given reassurances that for those who are HIV-infected, special care will be extended to mother and child both before and especially during labor and after delivery to prevent vertical transmission of HIV. Those who know their HIV-positive status will have a better opportunity than those who are unaware to take good care of their own health and to maintain their strength. If we are strong, we will be able to resist diseases better and will help delay the emergence of HIV symptoms for many years. In the interim, doctors are testing many drugs and vaccines that may offer hope for curing the disease. Nevertheless, those who know their positive HIV test results have the chance to plan for their children and families' future.

Perhaps we may resolve to work and save more for our children because we still have many good years ahead of us. We can live normally with other people and still be useful members of society.

*Sinjai*: While I am sharing this information with you, I would like to relay a message to the fathers that should your wives test positive for HIV, you should be tested too. For the newborns of an HIV-infected mother, it takes about a year before their HIV status can be ascertained. But in the near future, their HIV status will be able to be determined immediately after delivery. If I choose to be pregnant again, I will come and be tested like any other mother. I am happy for all mothers that the hospital is taking special care of those who may encounter this problem. In addition, there are hospital staff who are eager and willing to be both friend and counselor to every one of you and your families. Good luck to all of you.

**Background Voice**: With best wishes for a happy family life and with concerns for every mother's well being.

**Closing Caption**: "For These Reasons, the Hospital has Made Available HIV Blood Testing for Every Pregnant Woman."

**Background Voice** We have good news to tell everyone of you that the doctors have recently found a preventive measure to reduce mother-infant HIV transmission, which is antenatal administration of an antiretroviral drug to mothers who test positive. Now several government hospitals are offering this drug service without additional cost and this is going to be extended to all government hospitals throughout the country in the near future.

## **Appendix 2: Medication leaflet for HIV-seropositive pregnant women**

### **Medication Leaflet**

- Keep medication away from heat and moisture.
- Keep medication in a ziplock bag.
- Keep medication away from children.
- Take medication every morning and every night, as instructed.
- Come to get the medication each week at the ANC clinic.
- Bring all the old bags, used and unused, back to the hospital each visit.
- Do not give medication to any other person to take.

# Appendix 3: Information about PCP prophylaxis and antiretroviral drugs for infants

### General

- Reasons to give medicine.
- Action of medicine.
- When to start and how long to take the medicine.
- Dose, time, and route of administration of medicine. The counselor should assist her to identify a schedule which promotes ease of compliance.
- How to measure medicine (e.g., with a syringe, dropper, measuring spoon etc.).
- How to keep the medicine (i.e., protect it from light, or keep in refrigerator).
- Possible side effects (e.g., nausea, vomiting, headache, anemia, skin rash etc.).
- The importance of giving medicine continually. Discourage discontinuation of the medicine without consulting the doctor.

### Techniques for giving medicine to babies

- Prepare and measure the medicine. Use a syringe or soft plastic dropper, or a spoon for medicine mixed into drinks or food.
- With medicine in reach, sit in a firm and comfortable chair.
- Have a bib or towel on the baby. Take the baby in your lap.
- If you are right-handed, hold the baby in your left arm.
- Hold the baby's left arm with your left hand. Put the baby's right arm under your left arm around your back.
- Brace the baby's head and right shoulder between your left arm and chest so the baby's head stays still. Tilt the baby's head back a little.
- Put the medicine into the corner, towards the back and along the side of the tongue of the baby's mouth. This makes it harder for the baby to spit. Give a little amount of medicine at a time to prevent choking and spitting.
- Gently keep the baby's mouth closed until he or she swallows.
- Never yell or show anger. Speak softly and say kind things.
- When all the medicine is finished, hold your baby sitting up for a few minutes and cuddle and comfort him or her. Offer the baby water or juice.

### Sources:

Czarniecki L, Lerner-Weiss N (eds.). Your Child, Your Family, and HIV. National Pediatric & Family HIV Resource Center. Available at: www.pedhivaids.org/catalog/index.html

O' Hara MJ, Burr CK, Lerner-Weiss N. Asking Questions and Getting Answers–Choosing the best treatment for your child with HIV infection. National Pediatric & Family HIV Resource Center. Available at: www.pedhivaids.org/catalog/index.html

## **Appendix 4: Nutrition guideline for HIV-infected children**

### General nutrition guidelines for HIV-infected children

### 3 months

 Begin to feed ground rice with soup, and ripe banana so the baby will learn to feed from a spoon.

### 4 months

• Begin to feed egg yolk, ground liver, and stewed beans to add more Vitamin A, B<sub>1</sub>, B<sub>2</sub>, iron, and protein to the diet.

### 5 months

 Begin to feed fish, ground vegetables and pumpkin in order to add more protein and vitamins and minerals.

#### 6 months

• Replace milk with solid foods once a day. It should consist of either ground rice with egg yolk and vegetable, or ground rice with liver or fish or stewed beans. Give banana as a dessert.

### 7 months

Begin to give ground meat and whole egg.

### 8-9 months

• Give 2 solid food meals a day.

### 10-12 months

• Give 3 solid food meals a day. But if the baby can eat only a little at a time, 4 solid food meals is possible.

### Nutrition guidelines for HIV-infected children with specific illnesses

### Food for a baby with anorexia

Anorexia may result from many causes such as HIV, medication, sores in the mouth and esophagus, dysphagia (difficulty in swallowing), fever, and loss of appetite. These may cause weight loss, decrease in body fat and failure to thrive. The baby should be encouraged to eat by using the following techniques:

- Serve the baby his/her favorite food in a relaxed atmosphere.
- Serve a small amount of food, but several times a day.
- Provide meals high in protein and calories; avoid candy and soft drinks.
- Serve fruit between meals.
- If the baby has no oral problems, provide tasty food to motivate the baby's appetite.
- Take good care of the baby's mouth and teeth.

### Food for a baby with oral problems

Yeast infection of the mouth (thrush) and esophagus may cause difficulties in swallowing. To help the baby eat without pain and without irritation to the gastrointestinal tract, the food needs to have the right texture and temperature. The following techniques may encourage the baby to eat more:

- Provide warm or cool food. Avoid food that is too hot or too cold.
- Avoid hard and rough food.
- Serve soft food such as scrambled eggs or thick steamed rice.

- If necessary, use a dropper or straw for feeding a liquid diet to avoid irritation and mouth sores and for easy swallowing.
- Take good care of the baby's mouth and teeth.

### Food for a baby with nausea and vomiting

Nausea and vomiting can cause electrolyte imbalance and/or dehydration. If a baby has nausea or vomiting, the following techniques can be used:

- Serve an easily-digested diet (soft diet). Avoid greasy, bad smelling, and bad-tasting food. Encourage liquids.
- Keep food amounts small, but serve several times a day to prevent the baby from having an empty stomach.
- If necessary to rehydrate, use a dropper with clear and cool water and oral rehydration solution (ORS).
- Provide somewhat salty food. Avoid sweet food as it can cause nausea.
- Don't lie the baby flat immediately after meal.
- Take good care of the baby's mouth and teeth.

### Food for a baby with diarrhea

For a baby with diarrhea, the following techniques can be used:

- Keep food amounts small, but serve several times a day. Food should be soft such as rice porridge or steamed rice.
- Provide food high in protein and calories, but low in fat.
- Provide ORS to prevent dehydration.
- Stop feeding cow's milk or formula. Substitute soy-bean formula or some kind of milk specially produced for the baby with digestion problems.

# Appendix 5: The Bangkok Collaborative Perinatal HIV Transmission Study Group

The following are current and past collaborators in this research group:

### Siriraj Hospital, Department of Obstetrics and Gynecology

Chaiporn Bhadrakom, Prapas Bhiraleus, Pongsakdi Chaisilwattana, Pattrawan Chaiyakul, Amphan Chalermchokcharoenkit, Pichai Charoenpanich, Duangkamol Chevatadavirut, Peerapong Inthasorn, Wanida Lokapathana, Jirasak Manassakorn, Somchaya Neungton, Prasit Patanapanich, Phakphum Phophong, Ratana Prechanont, Jerawan Prymanee, Prayao Rattananikhom, Anuvat Roongpisuthipong, Suthi Sangkarat, Korakot Sirimai, Pavit Suchritpongsa, Taviponk Suvonnakote, Sommai Toongsuwan

### Siriraj Hospital, Department of Pediatrics

Kitti Angsusingha, Urapon Boonprakob, Sanay Chearskul, Kulkanya Chokephaibulkit, Siriluck Lohwithee, Wimolsri Phuakpoonphol, Sirirat Pichitchaichan, Kanokporn Tosasuk, Montri Tuchinda, Nirun Vanprapar

### Siriraj Hospital, Department of Microbiology

Rutt Chuachoowong, Suda Louisirirotchanakul, Chantapong Wasi,

### Rajavithi Hospital, Department of Obstetrics and Gynecology

Suvanna Asavapiriyanont, Pratharn Chinayon, Udom Choawarin, Pornsom Hutacharoen, Boonthai In-neam, Gitipong Kaewchaiyo, Chantima Kannasoot, Surasak Kaoiean, Sasitorn Leampojara, Yunyong Mangclaviraj, Boonsom Mitprapant, Varathip Otakanon, Chumnian Rithiron, Suvadee Sangkasuwan, Jaruwan Sawakwan, Sunee Singhaneti, Wimol Siriwasin, Smai Supatosa

### Queen Sirikit National Institute for Child Health

Somchoke Chanasongkham, Tawee Chotpitayasunondh, Sunthorn Horpaopan, Ratchanee Kulvisuthpravit, Pimsiri Leowsrisook, Bongkoch Phasukdee, Warunee Punpanich, Vilai Ratrisawadi, Varaporn Sangtaweesin, Anant Sawatanaviroj, Prathum Sojirat, Wanida Suteewan, Naris Waranawat

### The HIV/AIDS Collaboration

Anna Bennetts, Nartlada Chantharojwong, Rutt Chuachoowong, Bongkoch Jetswang, Jirasak Laosakkitiboran, Khanchit Limpakarnjanarat, Chomnad Manopaiboon, Timothy Mastro, Philip Mock, Thananda Naiwatanakul, Kanchana Neeyapun, Waranee Pokapanichwong, Nathan Shaffer, RJ Simonds, Natapakwa Skunodom, Wendy Supapol, Achara Teeraratkul, Bruce Weniger, Nancy Young, Prayoon Yuentrakul

### Centers for Disease Control and Prevention, Atlanta

Timothy Dondero, Eve Lackritz, Timothy Mastro, Philip Nieburg, Nathan Shaffer, RJ Simonds, Bruce Weniger, Nancy Young

### Ministry of Public Health of Thailand

Siripon Kanshana, Chaiyos Kunanusont, Wiput Phoolcharoen, Sombat Thanprasertsuk